What young people mean when they say...: The information and support needs of siblings and children of cancer patients.

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Abstract

This research project investigated the lived experience of young people between the ages of 9 and 19 years who have a parent or sibling diagnosed with cancer. The study aimed at investigating the needs of these children specific to information, supports, and communication. A cancer diagnosis within the family can be traumatic and impact all members, yet children or siblings of cancer patients tend to be overlooked due to a high focus on the sick family or member. Many of these children face adjustment difficulties across all areas of life, including at school, emotionally, socially, and mentally. Siblings and children were recruited from cancer support agencies via invitation. Once families had expressed interest in allowing their children to participate and had provided consent, one-on-one interviews were conducted with these children in Christchurch. Questions explored the experiences of these children and the needs which they saw as unmet. Participants were asked about their experiences having a family member diagnosed with cancer, what has helped them cope, what they would like to know more about, and what supports they would find beneficial. Results highlighted that children may face many changes when a family member is diagnosed with cancer, as well as requiring various types of support and communication. In addition to facing family separation, they are more time-conscious, and there was an emphasis on every child being different. Children require flexibility and awareness of supports and information, with a high need of communication from parents. By having children articulate their thoughts and feelings in their own words regarding their experience of having a family member diagnosed with cancer, it can be valuable to organisations and healthcare professionals who interact with these families so that the best information, supports, and resources can be provided to this population.

Chapter 1 – Introduction.

"Every day may not be good, but there is something good in every day".

(Alice Morse Earle).

Cancer is a serious, complex illness, with many different types, and affects people across the lifespan. This includes all those close to the person who receives the diagnosis, as it can create a strain on the family. With many components involved in cancer and treatment, there are many disruptions for all members (Wilkins & Woodgate, 2005). These disruptions tend to impact the schedules and social activities of everyone as the patient is at the hospital frequently (Wilkins & Woodgate, 2005). Especially in New Zealand with many having to travel hours to get to a cancer treatment centre and stay for extended periods of time (Porteous, Peterson, & Cartwright, 2018). Much of the earlier research investigated the psychosocial effects on the parents and, within the past couple of decades, has moved on to the siblings and children, as it has been argued that the effects of the illness should be extended to the whole family (Alderfer et al., 2010). However, there is still little information and mixed findings for this group, as well as a few issues hindering the obtaining of more representative groups (Long, Goldish, et al., 2015; Patterson, Millar, & Visser, 2011). This includes parents worrying that by talking about the illness it could affect the child further (Ghofrani, Nikfarid, Nourian, Nasiri, & Saiadynia, 2019), and those who do participate tending to be more readily available due to proximity to cancer treatment centres.

For children who have a family member diagnosed with cancer, it can be just as hard for them as it is for the patient, especially if it is a parent who is unwell and the children are still dependent on them (Golsäter, Henricson, Enskär, & Knutsson, 2016; Karidar & Glasdam, 2018). Without the appropriate and suitable information, this can lead to limited understanding, higher levels of anxiety, and poorer communication within the

home (Karidar & Glasdam, 2018). There are mixed findings on whether the child should be told of their relative's cancer diagnosis, with parents either not being able to because of the time spent away with the ill child (Porteous et al., 2018), or them wanting to protect the child whilst the ill parent goes through treatment (Karidar & Glasdam, 2018). Age also plays a part when it comes to discussing the illness with the child, as the younger they are the less cognitively developed they are, which can then impact their understanding (Turner et al., 2007).

Research has found that one of the main social supports that can help young people adjust to having a family member diagnosed with cancer is better informational support (Murray, 1999), yet when looking at what Aotearoa/New Zealand has for this demographic, this is very limited. With more than 100 cases of childhood cancer diagnoses reported each year in Aotearoa/New Zealand (Ballantine et al., 2017) and many more for adults, this highlights a need for more information resources and supports to be designed and developed to help families adjust. The information needs to be more developmentally appropriate for all ages and situations.

In Aotearoa/New Zealand, cancer accounts for almost one-third of deaths (Blakely et al., 2010), with approximately 540 new cancer cases per 100,000 people (Morton, 2018). When looking at support websites for cancer patients and their loved ones, there is little information available for young people. There are support systems such as *SuperSibs!* (Long, Goldish, et al., 2015) and the *Providence Family Programme* (Nelson, 2016), but without adequate information and communication, these supports are less likely to be accessed or not used to their full capacity. With organisations like CanTeen NZ, the Child Cancer Organisation, and the Cancer Society in New Zealand, young people have websites to turn to with resources such as support/peer groups. However, resources and information are still lacking for this population in comparison to other countries such as Australia.

In New Zealand, there are only two known studies which address the needs of the children and siblings of cancer patients, and only one is a published study (Lamb, 2015; Porteous et al., 2018). Although both utilised a qualitative methodology and gave a better insight into the experiences of the siblings, neither investigated the experiences of the children. By investigating their experiences from their own perspective, it allows for a deeper understanding of the experiences that these young people go through, due to the detailed data and analysis of it (Van Manen, 1990). The research refers to cancer and the process as an experience (Murray, 1998), which emphasises the need for more specific, in-depth research which asks these young people about their experience and how they understand the illness. This underpins the phenomenological approach (Lopez & Willis, 2004); reflecting on the lived experience of a phenomena (Van Manen, 2016).

Due to the lack of resources and support for this population, especially within Aotearoa/New Zealand, there is a need for more research to be carried out so that this gap can be appropriately and effectively addressed. Although the findings from international studies can aid in the understanding of an experience, each country is made up of different cultures and perspectives. Because of this, different cultures perceive and experience life events differently and it is important to approach health-related matters from a cultural perspective (Mystakidou, Parpa, Tsilika, Katsouda, & Vlahos, 2004). In a country where cancer rates across all ages are some of the highest in the developing world (Morton, 2018), the perceptions and understandings of the illness may vary from a country where the rates are lower. Therefore, the purpose of this study is to explore young people's perceptions of the support, information, and communication available to them when they have a parent or sibling with cancer. The aim for this research is to:

- Understand the perceptions of children and siblings about their experiences, in order to inform a more needs-based approach for the development of better support and resources.

As a student within the Child and Family Psychology programme, I am interested in the development of young people under the age of 18 years. I have studied psychology for 5 years and have a passion for better understanding how young people cope and persevere through tough situations, so that I can better serve them and help others to do the same. Over the past few years I have worked and volunteered for many child and adolescent-focused organisations which have helped develop my passion for helping these individuals cope and succeed. From a mental health perspective I believe that if our mind is healthy, then we are better able to cope with what we experience. The reason for choosing this topic is because it fits within my passion for helping and supporting young people. When discussing potential research topics, I discovered that there was a need for better resources and support for young people who have a family member diagnosed and living with cancer, especially within the Aotearoa/New Zealand context.

Structure of Thesis

In Chapter one I have introduced myself as the researcher, outlined the purposes for the current study, and included a brief overview of research currently available.

Chapter two presents an overview of the relevant literature and identifies the limited research which relates to an Aotearoa/New Zealand context.

Chapter three outlines the methodology utilised within the current study to answer the questions and objectives.

Chapter four presents the research design and method, including a discussion on ethical considerations, and methodological rigour.

Chapter five presents the results and the themes that arose from the research. Chapter 6 discusses the finding limitations of the research, recommendations for future work, implications for practice, and a conclusion.

Chapter 2 – Literature Review

"People would always ask me how she was doing, never how I was doing. I was suffering just as much as she was – not physically, but emotionally".

(Murray, 1998)

The following chapter reviews literature which investigates the experiences and needs of children who have either a parent or sibling diagnosed with cancer. Literature exploring the feelings, reactions, and changes that the children experience have also been reviewed to help further the understanding of this group. Subheadings will be used to make it easier and clearer to present the different subtopics with findings under each.

Electronic databases were used by the researcher to find the most inclusive collection of literature relevant to the study. These included Google Scholar, the University of Canterbury Library catalogue, and Medline. Search terms included "parental cancer", "children" "adolescents", "coping", "needs", and "sibling cancer". Results were then further limited to the past 10 years so that the information is more recent. However, in some cases as with reviews, some older research was used when relevant and insightful. Literature was further filtered by age of participants, with the age range being 7-19-years-old due to cognitive ability and fitting within the age range of the current study. In addition, reference lists of articles most closely pertaining to the topic were searched. The literature search yielded a total of 16 articles on parents with cancer, including one review article and 14 articles on children with cancer.

For the purpose of this study, individuals who are living with cancer will be referred to as the "patient", and those who are in remission and have finished treatment will be referred to as "survivors". The brothers/sisters of these individuals will be referred to as the "siblings" and the sons/daughters of patients will be referred to as the "children".

Overview

Cancer is the second leading cause of mortality internationally, with 1 in 6 deaths attributable to cancer (World Health Organisation, 2018). It can affect any part of the body and can be a burden both economically and within families, especially in families with young people. Yet, there are still many misconceptions about the illness. In a survey carried out by Silver and Silver (2013), it was found that 5% of adults who were teenagers when their parent was diagnosed said that they knew a lot about cancer and what was going on. Siblings though, due to the preoccupation that the parents have with the ill child, are kept less in the loop (Hamama, 2010), which can lead to feelings of worry, anxiety, confusion, and sadness (Porteous et al., 2018). Parents tend to avoid questions about cancer and death out of protecting the child from negative feelings, preserving family memories, or avoiding confusion (Kobayashi, Heiney, Osawa, Ozawa, & Matsushima, 2017). However, some reports show that parents confirm open communication helps to alleviate distress (Meriggi et al., 2017).

Impact on the whole family system.

When a family member is diagnosed with cancer, all family members are affected and distressed (Houtzager, Grootenhuis, & Last, 1999). For the children and siblings, as they start to contemplate their family member's mortality, distress is heightened (Ellis, Wakefield, Antill, Burns, & Patterson, 2017). The older they get, the more pronounced this awareness is due to an increased understanding of the diagnosis (McDonald, Patterson, White, Butow, & Bell, 2015). With many components involved in the diagnosis and treatment of cancer (treatments, side-effects of treatment, and hospital visits), there are many disruptions for all family members. These disruptions tend to impact the schedules and social activities of everyone as the patient is at hospital frequently (Wilkins & Woodgate, 2005). Within New Zealand, this is even more prevalent as many families have to travel long distances to hospital and stay for extended periods of time (Porteous et al., 2018).

From a family systems perspective, it is important to investigate the impact that cancer has on the whole family, so that the functioning of each individual family member can be better understood, especially in regard to the reorganisation and adaptation that they experience (Alderfer & Kazak, 2006; Finch & Gibson, 2009; Wilkins & Woodgate, 2005). The Family Systems Theory posits that all members within the family interact with and influence one another. The condition of one impacts all others due to being a system comprising of many interdependent systems (marital, parental, siblings, and child) (Bowen, 1993; Faulkner & Davey, 2002). The severity and uncertainty of cancer is devastating for each member of the family system (Murray, 1998; Murray, 1995). Not only is the patient affected by the diagnosis, illness, and demands, but also the spouse, child, and sibling (Finch & Gibson, 2009; Wilkins & Woodgate, 2005). This impact may be more noticeable when it is a parent who is diagnosed, due to the dependency that the child still has on them, and other factors which can be impacted (McDonald et al., 2015). For instance, the marriage quality (e.g. conflict) can affect the well-being of the parent or patient, which in turn can affect the well-being of the child (Compas et al., 1994).

A cancer diagnosis can lead to strong, negative feelings such as worry, sadness, jealousy, guilt, 'walking on eggshells', anger, role changes within the family, added responsibilities, marital discord, physical and emotional changes in the patient, emotional unavailability, and even conflict (Davey, Tubbs, Kissil, & Niño, 2011; Faulkner & Davey, 2002; Silver & Silver, 2013). Much of this may be intensified if the young person is also going through adolescence. Because of less parent availability for either physical reasons (e.g. being at the hospital) or emotional reasons (e.g. distressed themselves), and having less contact with health professionals, this increases the likelihood of unmet needs (Long, Marsland, & Alderfer, 2013). Despite the undesirable outcomes when a parent or sibling has cancer, the outlook is not all negative. There have been a plethora of positive outcomes

regarding coping, growth, and maturity. These include greater empathy for others, stronger familial bonds, better communication, and greater levels of maturity (Kennedy & Lloyd-Williams, 2009; Silver & Silver, 2013). This knowledge is beneficial, as collectively it can increase understanding and awareness of what helps.

Hence awareness and understanding that each member will be impacted differently, with effects not being instant is important to consider. Although observing the current effects of cancer provides an insight into the impact on the family system, longitudinal work that examines the effects over time furthers this understanding (Faulkner & Davey, 2002). This knowledge can then answer questions pertaining to mechanisms by which a familial cancer diagnosis can impact the functioning of the family unit, such as the strength of the familial bond and the level of inclusion from all members. Granted that the majority of the research is cross-sectional (Ellis et al., 2017; Long et al., 2018), it does help researchers understand the experiences of children and siblings. This provides more information on how they cope within the family and what their needs may be.

Even though the majority of the literature focuses on the cancer patients and their spouses or parents, there has been a shift in research over the past few decades, with a focus on young people who have a parent or sibling diagnosed with cancer (Patterson, McDonald, White, Walczak, & Butow, 2017). Studies which investigate their experiences show that they are at risk of developing post-traumatic stress and other psychosocial issues (Kamibeppu et al., 2010). When not informed, supported, or involved, this risk is even more pertinent. For adolescents, due to the conflict arising between wanting to remain close to the family and wanting to become more independent, this can create more discord (Patterson et al., 2017). Across research, age is important to consider, as needs of older children vary from those of younger children (Chowns, 2013; Maynard, Patterson, McDonald, & Stevens, 2013).

When facing a difficult situation, feelings of distress, confusion, and worry can be heightened. The relationship between elevated levels of distress and unmet needs has been investigated more recently during the past decade in siblings and offspring of cancer patients (Patterson et al., 2014; Patterson et al., 2013; Patterson et al., 2017; Patterson, Millar, et al., 2011). In a study of 405 adolescents and young adult (AYAs) offspring and siblings, authors found that AYAs had moderate to high levels of distress (Patterson et al., 2017). This was more pronounced the more needs they reported as unmet. When matching scores from the Kessler 10 Distress Scale to scores on the Sibling Cancer Needs Instrument (SCNI) and the Offspring Cancer Needs Instrument (OCNI), results showed that elevated distress was associated with more unmet needs. Specifically, the more distressed the child was, the more unmet needs they had in addition to a stronger level of need. Consistent with previous studies (Wilkins & Woodgate, 2005), the most commonly reported unmet needs included information, time for themselves and recreation, support on how to cope with feelings, and support from peers and those going through a similar situation (Patterson et al., 2017). Although this study took a quantitative approach, these findings display the association between unmet needs and higher distress, which is shown to contribute to poor functioning. Additionally, through including a large age range, researchers were better able to investigate any age-specific differences amongst participants. Yet the results lack in depth of understanding when investigating the specific experiences of offspring and siblings due to being a quantitative approach. Though this information has proven to be useful in gaining insight into the experiences, not many studies investigate the needs which go unmet. With equally high amounts of both siblings and children endorsing information and supports as important (Patterson et al., 2017), and through utilising qualitative methods, health professionals and families will be better guided to meet these. The following subsections

elaborate upon these needs and experiences, with a focus on the main unmet needs (information and support) through reviewing the qualitative literature of the past decade.

Children of parents living with cancer.

When a parent is diagnosed with a serious illness like cancer, disruptions and changes are experienced by everyone within the family (Faulkner & Davey, 2002). Earlier research predominantly focused on the ill parent and their spouse, seldom investigating the impact upon children (Compas et al., 1994; Faulkner & Davey, 2002). However, there are age-dependent factors to consider. For a child who is still dependent on the parent, the illness is more noticeable and may be more confusing due to a lack of understanding (Karidar & Glasdam, 2018). For older children, it can be more stressful and distressing due to a better understanding of the severity, increased responsibilities, and decreased socialising (Kennedy & Lloyd-Williams, 2009; Phillips, 2015; Silver & Silver, 2013), especially as they are navigating the changes they are experiencing and the need for autonomy (Rodriguez, Groarke, Dolan, & Macneela, 2018; Silver & Silver, 2013). Having more responsibilities and having to mature a lot faster, they may take on a parental role (Patterson et al., 2017). Previous studies have shown that the needs of offspring were similar to those of adult caregivers of patients. Due to a plethora of changes and disruptions to daily life, in addition to the distress of the illness, children and siblings of cancer patients have been shown to be at a greater risk of poorer outcomes (Huang, O'Connor, & Lee, 2014; Long et al., 2018; Thastum et al., 2009). These include posttraumatic stress, anxiety, depression, and poor academics. Yet, research displays mixed findings and this area is still less understood than the impact of cancer on spouses (Compas et al., 1994).

Available research indicates other factors which may be impacted by the cancer, in turn increasing the risk of poorer adaptation and unmet needs (McDonald et al., 2016). These include added strain on the marriage of the parents and the functioning of the family, due to

illness-related stressors (Faulkner & Davey, 2002). From an ecological perspective, the closer the family and subsystems are (parent-child, siblings), the greater the impact on coping and adjustment (Rodriguez et al., 2018). These findings highlight age-dependent differences in needs and functioning, and the varying degree of information required (Silver & Silver, 2013). Where younger children may lack understanding of the illness, older children are much more cognizant. It tends to be when the patient has reached the terminal phase that the younger children know about the illness (Kennedy & Lloyd-Williams, 2009). Yet, one study argues that they are much more sensitive and aware than believed, with reports that some young children could guess the bad news prior to being informed (Huang et al., 2014), whether by sensing changes or putting things together (e.g. hearing about having a lump). Future research would benefit from determining this, as those who are not told until later display anger, confusion, and isolation (Davey et al., 2011).

The younger the child is, the more dependent they are, whereas older children start to become more independent. Hence, when investigating the impact of parental cancer, it is important to look at the family as a whole. Because of the different subsystems within the family, such as the parent-child dyad, everyone is impacted and copes differently (Faulkner & Davey, 2002). For distress to be minimised amongst children, understanding the psychosocial consequences and needs of this group are paramount (Huizinga et al., 2011). As a result, this information will then guide health professionals and support services in developing appropriate resources and supports. The studies in this review focus on the impact, the needs identified by the children and adolescents, focusing on information and support needs, and a look into the available supports and resources for children between the ages of 7 to 19-years-old.

Impact of Parental Cancer

Despite the increase in research on children, the majority focuses on how cancer affects the patient and their spouse, with understanding and information lacking in scope and depth (Compas et al., 1994; Faulkner & Davey, 2002). Especially on young people aged 10-24 years (Ellis et al., 2017). This is not surprising, as for many years children have been excluded from their parents' treatment plans. Resulting in feeling overlooked or ignored (Faulkner & Davey, 2002). What is troubling is that more than a third of women diagnosed with cancer have at least one school-aged child (Lewis & Hammond, 1996). This indicates a high proportion of children who are at risk of developing issues related to mental health and school life.

Approximately 10% of all cancer cases in the United Kingdom are of those who are between the ages of 25 to 49 years (Cancer Research UK, 2018), with higher rates in New Zealand (Morton, 2018). Despite being hard to establish the specific number of children and young people affected by chronic parental illness, specifically cancer, it is reasonable to assume that the number is substantially high (Ellis et al., 2017). A cancer diagnosis not only affects the patient, but it also extends to family, friends, and even the wider community, with an estimated US$1.16 trillion economic cost reported in 2010 alone (World Health Organisation, 2018). In addition to the financial impact on the family, emotions, psychological states, and development can all be impacted also.

Dealing with cancer and its treatment is considered a "family affair", with everyone affected by the changes (Hagedoorn, Kreicbergs, & Appel, 2011). Feelings like worry and anxiety due to the disruptions to daily life and the unpredictability of the illness are prevalent, especially when families have dependent children and young adults. Regardless of whether the cancer is not advanced, terminal or has a positive prognosis, children and young adults who depend on their family psychologically, physically, socially, and economically are more greatly affected (Huang et al., 2014; Syse, Aas, & Loge, 2012). As a parent begins to face the

realities of cancer, they may display higher stress and depressive symptoms (Lewis & Hammond, 1996; Semple & McCaughan, 2013). Separately, parental cancer and depression can create strain within the family, due to poorer parenting, less availability, and changes in mood (Claessens, Engel, & Curran, 2015; Kiernan & Huerta, 2008; Lewis & Hammond, 1996). So, not only does the child face lack of physical availability, but also emotional unavailability, mood swings, irritability, and impatience (Davey et al., 2011; Lewis & Hammond, 1996). Both cancer and depression together can heighten the risk of developing poorer outcomes for a child.

Recent research indicates that children are at a higher risk of psychosocial problems such as poorer mental health, higher distress, stress, and anxiety (Morris, Martini, & Preen, 2016; Rodriguez et al., 2018). Albeit there are mixed findings pertaining to age and gender differences (Rodriguez et al., 2018), research does indicate higher distress levels in girls and more externalising problems amongst boys (Huizinga et al., 2011; Morris, Turnbull, Preen, Zajac, & Martini, 2018). Whereas younger children are more confused, adolescents are shown to experience more internalised issues such as anxiety (Morris et al., 2016; Rodriguez et al., 2018; Silver & Silver, 2013). This is heightened due to the changes they themselves experience and the added responsibilities and demands post-diagnosis. Yet research is mixed on these findings. Potential reasons why some adolescents cope more successfully have been explored. At an individual level these include resilience and ability to deal with stress and emotions. From a contextual level, family functioning, cohesion, and social support are also suggested to be protective factors (Rodriguez et al., 2018).

Additionally, much of the research focuses on the impact that maternal cancer has on children but not on paternal cancer and its impact. This limits the generalisability as there are different factors which affect how the illness can impact the child and to what extent. This is an important area that requires more focus and investigation, as it has been speculated that

children may be impacted differently, or more so, by paternal cancer. This is suggested to be due to the poorer prognosis of male cancer and the differences in relationships between mother, father, and child (Morris et al., 2018; Thastum et al., 2009). Although understanding the experiences of children is beneficial, it offers little guidance to service providers when developing supports and resources (Patterson, Pearce, & Slawitschka, 2011). Thus, research would benefit greatly from unpacking the specific needs through understanding these experiences.

Factors Impacting Needs

Offspring of cancer patients face many challenges and changes over the course of their parent's cancer (Lewis & Hammond, 1996). These include less socialising, increased responsibilities, and becoming another caregiver within the home (Huang et al., 2014). Research also reports different challenges faced by those living rurally (Garrard, Fennell, & Wilson, 2017), yet more work is required to unpack this. How they respond to these challenges varies depending on their age (Ellis et al., 2017; Morris et al., 2018). For adolescents, as a result of the stress, increased responsibilities, isolation, and disruptions faced (Morris et al., 2018; Sieh, Visser-Meily, & Meijer, 2013), they display higher levels of anxiety and depression (Compas et al., 1994). In Westernised cultures, where independence is valued (Morris et al., 2018; Silver & Silver, 2013), facing the potential of family bereavement compounds this (Chowns, 2013). These and other factors can lead to higher unmet needs and higher distress as a result, including increased conflict for adolescents between meeting their developmental needs and the needs of the family (McDonald et al., 2016). Thus, it is important to explore and understand these factors better before discussing the met and unmet needs of this population.

Despite variations in the literature over what factors impact needs, awareness of these potential risk factors can aid professionals to provide better support for children during the

course of the parent's illness (McDonald et al., 2016). In one study it was found that having a shorter time since diagnosis can lead to increased levels of unmet needs (McDonald et al., 2016), and this could be a result of the family going into survival mode due to the initial shock and changes. However, due to the inconclusiveness of the findings, more research is required (Davey, Kissil, Lynch, Harmon, & Hodgson, 2012). Although Davey et al., (2011) did not find variations based on demographic factors such as length of time post-diagnosis and the child's age, factors like the demographics or the functioning of the family may have impacted this. Looking at all components in a holistic sense is crucial (McDonald et al., 2016) due to the many factors which may act as buffers or hinderers. Poorer family functioning and paternal cancer are shown to increase the number of unmet needs (Walczak, McDonald, Patterson, Dobinson, & Allison, 2018). Notwithstanding, paternal cancer research is lacking, potentially owing to the proximity of the mother to the child and her impact on their development.

Regardless of the role of the parent, the family as a whole is a salient factor, having a direct impact on the child's growth and development; especially during the early years (Bronfenbrenner & Morris, 2006). As McDonald et al., (2016) demonstrated, if the functioning is poor, this can contribute to unmet needs and issues within the family. Specifically, the findings displayed significant effects on both the number of unmet needs and distress, especially regarding expressiveness and conflict. Interesting to note is that information needs were less likely to be met when higher cohesion was reported (McDonald et al., 2016). As suggested, cohesion could inhibit the parents from appreciating the level of information that their child requires, in turn preventing the child from asking, resulting in a lack of communication. By making healthcare professionals aware of the offspring and the family functioning, distress and unmet needs could be decreased.

Needs identified by young people

Over the past few decades there has been a considerable increase in research on the experiences of children of cancer patients. Published studies have shown that children experience significant changes and challenges when their parent is diagnosed with cancer (Lewis & Hammond, 1996). This is especially noticeable in adolescents and young adults, who take on many more responsibilities and have to sacrifice more than their younger counterparts (Kennedy & Lloyd-Williams, 2009). Additionally, as noted in one study their needs may not be appreciated by important people within the context of their parent's illness (Ellis et al., 2017, pp. 2). Yet research on this is lacking (Ellis et al., 2017). This is concerning as it contributes further to unmet needs and issues such as isolation and stress (Kamibeppu et al., 2010). By understanding a young person's experiences and needs from their perspectives, researchers and health professionals are better able to facilitate coping and adjustment through the development of resources and supports (Ellis et al., 2017).

Offspring report an array of different needs, with consistency across published studies (Huang et al., 2014; Walczak et al., 2018). In the development of an instrument which aims at assessing the psychosocial and unmet needs of offspring, participants reported 8 different 'need domains' (Patterson, Pearce, et al., 2011). These include information, peer support, expressing and coping with feelings, respite and recreation, support for carers, supportive education and work environment, family factors, and access to support services. Of these, the highest endorsed and commonly reported needs are information and support (Ellis et al., 2017). Research consistently reports the importance of tailoring these needs to the offspring's age and gender (Ellis et al., 2017; Huang et al., 2014; Walczak et al., 2018). For example, girls are shown to want more information about future tests if their mother has breast cancer and a higher need for support from peers if they are adolescent age (Kennedy & Lloyd-Williams, 2009).

In a review of this research, Ellis et al., (2017) further reported three factors which appear to be crucial in the development of interventions for this group. These included age-appropriate information about the illness, support for communicating with important people within the context of the parent's illness, and a supportive environment which will enable them to open up and feel normal. With more emotional or psychiatric disturbance (e.g. distress, anxiety, depression) that the offspring may experience, research indicates a higher need for additional supports which are tailored to them (Niemelä et al., 2012). Through acknowledging and better understanding the differences amongst offspring, this information will provide insight into guiding the development of supports to match these needs. In addition it will make professionals cognizant of the difficulties faced by these young people. The following sections elaborate upon the needs touched upon, with a focus on the two commonly recurring needs, information/communication and support.

Information and Communication Needs of the Children

Studies have shown that children have a high need for information about their parent's cancer and require support in opening up that communication (Ellis et al., 2017). Access to information which is at a level that they understand is shown to help alleviate misconceptions which appear to be more frightening than the parent's actual situation. As a result, with their misconceptions dispelled, offspring display lower levels of illness-related anxiety (Semple & McCaughan, 2013). However, many children report hesitation in asking their parents questions out of fear of upsetting them and feeling that they cannot directly approach their parent's healthcare professionals (Kennedy & Lloyd-Williams, 2009). Similarly, parents also report their own reasons for not communicating with their children. Reasons for this include a lack of awareness of the offspring's distress, feeling guilt over not being able to fulfil their parenting role, worry about breaking down in front of their child, and not wanting to upset the child (Kennedy & Lloyd-Williams, 2009).

In a study reviewing the recent literature investigating the experiences of offspring, authors discovered that children want to be informed of the illness and seek factual information if they want to know more (Huang et al., 2014). Although many of the studies within this meta-analysis show that the majority of offspring in the studies were informed of the illness, there were differences in when this occurred. Some were informed right away, whereas others were told later. Reports also show that even before an accurate diagnosis, some offspring were aware of the possibility of their parents having cancer (Huang et al., 2014). This may be due to discussions of a lump being present or reading something at the hospital and making the connection. These findings indicate the sensitivity and levels of awareness of offspring, and thus highlight the need for parents and healthcare professionals to be aware of the child's needs. Additionally, Huang et al., (2014) also found that the understanding of offspring varied on an array of factors including their age and the information provided. With a lack of understanding, children may suspect the worst outcome. With sufficient, age-appropriate information, children are likely to display reduced levels of stress (Davey et al., 2011). Even with information provided, adolescents in particular reported a higher demand for information, claiming that their needs were not met (Huang et al., 2014). If information needs are met, feelings of isolation, helplessness, and confusion can all be reduced (Wong, Ratner, Gladstone, Davtyan, & Koopman, 2010). Within the past decade, there has been an increase in the understanding of offspring and their needs through their own perspectives (Kennedy & Lloyd-Williams, 2009; Patterson et al., 2017). Because children vary in their understanding of cancer, as well as the type and amount of information that they need (Huang et al., 2014; Silver & Silver, 2013), gaining their perspectives is vital (Patterson, Pearce, et al., 2011). The studies which have assessed this have discovered that children express a need for more accessible information which is at a level that they understand (Patterson, Pearce, et al., 2011), with a need for a wide range of

sources. Results from a study investigating the information needs of children found that children wanted a variety of sources, including parents, books, healthcare professionals, and the internet (Kennedy & Lloyd-Williams, 2009). The authors looked at the specific components of information needs, such as how, when, and by whom the children wanted it delivered. Gender differences showed that girls were more concerned about future tests and implications for their own health (Kennedy & Lloyd-Williams, 2009), particularly when the mother was diagnosed with breast cancer. Although no differences were found across ages, findings are mixed within the literature (Ellis et al., 2017). Furthermore, it was discovered that factors such as information which is not age-appropriate or having a lack of access to professionals are shown to hinder children from obtaining information (Kennedy & Lloyd-Williams, 2009).

One of the main components hindering access to information is poor communication. As research shows, both children and parents struggle to communicate (Kennedy & Lloyd-Williams, 2009). Yet, "communication is a two-way street" (Silver and Silver, 2013, p. 35). As Davey et al., (2011) showed, the poorer the communication, the more anxious, distressed, confused, and angry the child can get. Whereas if the communication lines are open, offspring are shown to understand and support their parent (Chowns, 2013), as well as having any misconceptions and unanswered questions cleared up (Phillips, 2015). To facilitate communication of information, especially about more difficult topics such as questions about death, support to do so was considered highly beneficial (Kennedy & Lloyd-Williams, 2009). Some offspring report that they do not have anyone within the family to talk to, with many reporting that they turn to external sources for information (Maynard et al., 2013; Rodriguez et al., 2018). A common theme across the literature is that every child is different in the type and amount of information that they require, as well as who they want it delivered by (Kennedy & Lloyd-Williams, 2009; Rodriguez et al., 2018; Silver & Silver, 2013).

Even with an increase in accessibility (e.g. books, the internet), information needs appear to be the most prevalent unmet needs of this population (Ghofrani et al., 2019). In a recent study conducted by Ghofrani et al., (2019), more than 50% of all children who participated reported information needs being unsatisfactorily met. Authors suggested that one of the main barriers were the parents. This was found during the recruitment stage of the study, whereby parents were concerned that by participating or discussing the illness, it would make the child overthink the illness, resulting in higher levels of distress. Yet research within this field indicates the opposite to be true. By not telling the child or them finding out the diagnosis or information from other, sometimes untrustworthy, sources, feelings of anger, confusion, anxiety, and distress can all be elevated (Davey et al., 2011; Ghofrani et al., 2019). Children want detailed information from diagnosis onwards (Semple & McCaughan, 2013), so by providing the child and family support to communicate, information will be delivered more timely and appropriately.

Support Needs of the Children

When facing the potential bereavement of a family member, children report a high need to be heard, understood, and supported (Davey et al., 2011). Forms of support vary, meaning different things to different individuals. Forms of support include being able to openly communicate with family, emotional support, peer support (e.g. support groups), and external support (e.g. counsellors, school). Due to changes within and outside the family, lack of parental presence, and emotional stress, support is a consistent need. Yet, similar to information and communication, supports are lacking, with many children often feeling overlooked, ignored, and/or inappropriately supported (Chowns, 2013; Davey et al., 2011). Without age-appropriate supports, the ability to cope well is limited due to increased feelings of isolation and fear (Davey et al., 2011).

Even with an increased focus on offspring, much of the literature reports on their experiences and descriptions of their functioning, with little attention given to their needs (Patterson, Pearce, et al., 2011), specifically whether or not they are being met. With this information, service providers are better equipped to meet the offspring's needs, especially when it comes to their support needs. In a study aimed at identifying the psychosocial needs of offspring, the authors developed a need-based measure which would target needs which were going unmet (Patterson, Pearce, et al., 2011). The first part was a qualitative exploratory method, whereby the participants were asked about their perceptions of the needs/unmet needs experienced, and the second was a quantitative phase which used the responses obtained in the first part to conduct a pilot test of the measure. Descriptions from the first part identified eight 'need domains': information, peer support, expressing and coping with feelings, respite and recreation, supportive education and work environment, family factors, access to support services, and support for carers (Patterson, Pearce, et al., 2011). Similar to other studies (Ellis et al., 2017), findings showed that support was one of the most important needs, with five of the eight being support-focused. Participants reported that they wanted support from peers, other teens in a similar situation, professional support for their emotional and mental well-being, and supportive environments where they could function well (Patterson, Pearce, et al., 2011). During the test pilot of the Offspring Cancer Needs Instrument (OCNI), authors discovered a high level of unmet needs amongst this group. More than 90% of offspring recognised 10 or more unmet needs, with over a quarter indicating more than 50. The most commonly reported unmet needs included support and understanding from peers, assistance with academic-related activities, and emotional support (Patterson, Pearce, et al., 2011). This indicates that offering support and services to offspring which promote greater communication and interaction with peers, thus alleviating illness-related stress is crucial for their ability to cope. This is in addition to supporting them to express and

cope with emotional reactions (Patterson, Pearce, et al., 2011). Due to the relational nature of adolescents and time spent at school, peers and teachers are prominent figures and can offer a strong sense of support for the adolescent (Silver & Silver, 2013).

Adolescents have been the main focus within the literature (Huang et al., 2014), due to the amount of turmoil families with adolescents face in comparison to families with younger children (Rodriguez et al., 2018). As a result, support needs will vary. Despite the variations in what is sought, both children and adolescents report difficulties in discussing the illness with their parents and want support from peers to increase feelings of normality (Ellis et al., 2017). Yet this need for support is higher for adolescents (Ellis et al., 2017). Even though the family environment offers support, as evident in one study (Maynard et al., 2013), adolescents report differences in how they act depending on who they are with. As one adolescent put, "I found that my friends know me like, really socially so they know, what to say and sometimes you just sort of act differently around your family than you do with your friends" (Maynard et al., 2013, p.692). However, this was only true for those who had a supportive friend group. For those who didn't, feelings of distancing themselves, abnormality, and isolation were reported (Chowns, 2013; Davey et al., 2012), with many preferring support from peers who have been through a similar experience (Maynard et al., 2013).

Age-specific 'teen' groups are shown to be one way of receiving this type of support. This is because of the genuine empathy and understanding received to help adolescent offspring feel 'normal' (Ellis et al., 2017). It is a space where they can meet with other young people in a similar situation, who they can learn from and openly discuss things with, which their other peers may not understand. Similarly, understanding and support offered by friends has been reported as very important for the coping mechanism of adolescents, due to feeling cared for, validated, and helping to distract them (Maynard et al., 2013; Patterson,

Pearce, et al., 2011). There was also a sense of relatability and comfort provided by others in a similar situation that they may not have received from friends (Phillips, 2015).

Similarly, school is another important area of support due to the amount of time spent there in comparison to at home. It has been shown to be a place of peace and consistency (Chowns, 2013), as well as providing a sense of normalcy and alleviating stress related to their situation (Kennedy & Lloyd-Williams, 2009; Phillips, 2015). However, in a recent study by Chowns (2013), this was not the case. The theme of support within the school produced the strongest feelings and most substantial data, with adolescents reporting that school was a cause of stress due to schoolwork and lack of understanding from teachers. This was a result of behaviours from teachers who showed a lack of awareness of the offspring's situation, contributing to further stress (Chowns, 2013). As results show, with a lack of awareness, teachers assumed that late or poorly completed work was due to laziness or incompetence, rather than an inability to concentrate due to what was going on at home. Offspring wanted to feel genuine support and understanding from their teachers and other staff so that they were given equal chances to learn and thrive (Chowns, 2013). With the stress and uncertainty of having a parent diagnosed with cancer, having teachers who are aware and informed will establish a supportive environment to escape to. Additionally, adolescents reported needing help within the school to remain on task and to have professional support services available (Patterson, Pearce, et al., 2011). However, the way offspring are approached by the teachers depends on the way they want to be supported, as results across studies show variations in the needs of each child (Chowns, 2013; Ellis et al., 2017).

Even though there is an underrepresentation of ethnicities other than Caucasians, studies which investigate the needs and experiences of offspring from other ethnicities show consistent findings when it comes to the support that they require. In a study conducted with African American youth, results show that having a support group close to diagnosis and

throughout the entirety of their parents illness was important to them and their well-being (Davey et al., 2011). Furthermore, the more stressors present, the harder it is to cope, and a higher level of unmet needs is reported. For African American youth who face other external stressors such as racism, this can contribute to the level of family stress, increasing the susceptibility for negative outcomes. Due to being a collective, family-focused culture, the offspring show themselves to primarily rely on family support; differing from their Caucasian counterparts (Davey et al., 2011). These and other findings are all indicative that supports need to be tailored to individual needs: age, gender, and ethnicity. Offspring show a wide range of coping strategies (Davey et al., 2011; Maynard et al., 2013; Phillips, 2015; Phillips & Lewis, 2015), and findings will aid health professionals and service providers in developing appropriately tailored supports to meet these needs.

Evaluation of Supports and Resources

Supports

As identified in the literature, children require information about and support for the parent's illness (Ellis et al., 2017; Huang et al., 2014; Morris et al., 2016; Walczak et al., 2018). Yet there still seems to be a lack of information available. In a book recently published by Silver and Silver (2013), the authors discuss available resources for children in America. Camp Kesem, run by college students, is aimed at 6 to 18-year-olds who have a parent living with cancer or who are bereaved (Kesem, 2018). Children go on a week-long stay, where they take part in innovative, fun-filled programmes. There are over 100 locations throughout America, and in 2018 over 9,000 children were supported. There is no extra cost to the families whose children attend, alleviating some of the financial burden already on the family from other illness-related expenses (Kesem, 2018). Over 90% of parents surveyed stated that their children appeared to have greater confidence to talk more openly and said that they

would send them back. Overall, Camp Kesem demonstrates itself to be a beneficial and effective support.

Similarly, Canteen Australia provides resources and supports like camps for any 12 to 24-year-old who has been impacted by cancer in some way. Camps run by this organisation provide a safe place for the children to open up and share their experiences, in addition to fun activities and discussions of the illness. Canteen also offers other forms of support including online forums, support from peers and counsellors, and information-based tools to facilitate coping. Unfortunately, within Aotearoa, similar supports and resources tend to be tailored more towards patients; there are hardly any for children of patients. With high rates, of cancer within New Zealand (Ballantine & NZCCR Working Group, 2017), this is problematic as many children will continue to be overlooked and underserviced. Overall, although there are supports out there, the biggest hurdle is how little they reach.

Information Resources

Comparative to supports, there are a substantial amount of informative resources available. In a book titled *My Parent has Cancer and it Really Sucks* (Silver & Silver, 2013), authors supply concise, detailed, information over 14 chapters. Topics include exploring what cancer is, communication, potential changes, how to cope, and bereavement. All are achieved in teen-friendly language, incorporating quotes, anecdotes, and advice from other teenagers who have or are experiencing something similar (Silver & Silver, 2013). This resource is unique for a couple of reasons. Firstly, it is the only book like it available. Secondly, it aligns with some of the research (Davey et al., 2011; Huang et al., 2014; Wilkins & Woodgate, 2005), whereby feelings of loneliness are reduced and normality increased when offspring can relate to others; through the incorporation of advice from other peers (Silver & Silver, 2013).

Much of the information is targeted towards teenagers, with less for younger children. For example, the National Cancer Institute (2012) in America supplies a resource titled "When your Parent has Cancer: A Guide for Teens". Similar to the book by Silver and Silver (2013), advice from other teens is incorporated into this interactive booklet, with sections for them to tick the feelings they may be experiencing without having to verbalise it. Some teens may struggle to open up about what they are feeling, so by providing them with another way to express them is crucial. Covering a range of information pertaining to the illness and what to expect, there are sections on where they can access extra support and how to cope (National Institute for Health and Clinical Excellence, 2005). Other countries have websites providing similar resources, yet they still lack in scope and many families are not aware of them.

New Zealand has a varied range of resources for most ages, including a resource enabling open communication within the family: "Cancer in the family: Talking to your Children" (Cancer Society NZ, 2010). Communication and information extends to the whole family and health professionals. Through empowering parents to communicate, inclusion of the child is facilitated, as many report needing more open communication from their parents (Kennedy & Lloyd-Williams, 2009; Meriggi et al., 2017; Silver & Silver, 2013). Increasing accessibility, PDFs and Word documents have been created, in addition to information helplines which are free of charge to contact (Cancer Society NZ, 2010). More resources are needed to meet the needs and demands of children, specifically including a wider range of ages. Much of the research indicates a high need for more age-appropriate information (Ellis et al., 2017), yet most only target a specific age bracket. For example, New Zealand has more resources for younger children, whereas Australia supplies more for older children.

This is problematic as only one age group benefits. Overall, although the resources and supports outlined above are in-line with some of the current research, much still needs to

be done. Although there is an adequate amount of information available on the needs of children, little has been done to address this. Future research would benefit from investigating the effectiveness of existing resources and supports, and then using this information to develop more effective and helpful resources which meet the needs of children of cancer patients.

Siblings of cancer patients.

Similar to offspring, siblings of children with cancer are seldom looked at in research; the sick child and/or the parents dominate the literature (Houtzager et al., 1999). This may be due to their position in the family, whereby they are seldom at the hospital as the parents want to keep home life as normal as possible. Franklin et al., (2018) show that a child's cancer diagnosis extends to and affects siblings. Yet the knowledge and understanding is still limited in scope, amount, and conclusiveness (Wilkins & Woodgate, 2005), especially within New Zealand (Porteous et al., 2018). This is worrying due to the high rates of cancer, especially amongst young people, and with rates continuing to increase (Ballantine & NZCCR Working Group, 2017). During the 1980s onwards, awareness of and research into this group has increased, with a steady increase over the past decade (Long et al., 2018). Early work by Murray (1995) found that siblings reported feeling unimportant and overlooked, suffering as a result. However, there are only a few studies from the perspective of the siblings (Wilkins & Woodgate, 2005). Work by Houtzager et al., (1999) discovered that the emotional needs of the siblings were the least adequately met of all family members, with significant levels of anxiety and worry, feelings of isolation, and excessive worry for the parents and patient.

Needs of the Siblings

Similar to children of cancer patients (Walczak et al., 2018), there is consistency in the most commonly reported unmet needs. These include family communication, adequate

information, involvement in the care of the sick sibling, and support in maintaining normalcy (Wilkins & Woodgate, 2005). As the illness became more prevalent and noticeable, the needs were even more overlooked and unmet (Wilkins & Woodgate, 2005). Although many factors influence how well a sibling copes and adapts, the needs which are unmet (e.g. gender, age, contextual such as family functioning), are relatively consistent across the literature (Zegaczewski, Chang, Coddington, & Berg, 2016).

By obtaining the perspectives of the siblings, it provides a rich, detailed description of their experiences (Wilkins & Woodgate, 2005). In a review of the research, Wilkins and Woodgate (2005) found three themes produced by the literature: changing lives, intense feelings, and unmet needs. The latter then elicited a further four themes, including communication, adequate information, involvement, and support (Wilkins & Woodgate, 2005). When these needs go unmet, siblings display higher levels of anxiety, distress, fear, and a plethora of other feelings (Hamama, Ronen, & Rahav, 2008; Long, Goldish, et al., 2015; Patterson, Millar, et al., 2011; Porteous et al., 2018; Van Schoors et al., 2019). Therefore, they are at a higher risk of developing and displaying posttraumatic stress symptoms (D'Urso, Mastroyannopoulou, & Kirby, 2017) and it is more prevalent in female than male siblings (Kamibeppu et al., 2010). It is an outcome post-illness where the sibling has experienced trauma related to their sibling's illness (Alderfer, Labay, & Kazak, 2003). Without the proper support and communication about what is occurring and what to expect, siblings are at greater risk of higher levels of PTS.

Although communication does occur within families, it tends to focus on facts rather than feelings or fears (Wilkins & Woodgate, 2005). For children to adapt and function well, they need information about the illness, as well as a safe space to open up and be supported to do so (Long et al., 2018). In order for siblings to adapt and function well, it is crucial that professionals identify children most at risk and develop interventions which will help to

facilitate communication within the family (Long et al., 2018). Additionally, they concluded that increasing social support, supplying appropriate information, and providing opportunities to be involved were important to enable this.

Support for siblings is now becoming more prevalent in pediatric oncology (Gerhardt, Lehmann, Long, & Alderfer, 2015), but this group still reports high levels of unmet needs. A recent meta-analysis examined the psychosocial adjustment of healthy siblings and identified that they are at a higher risk of poorer outcomes (Long et al., 2018), specifically older siblings (Kaplan, Kaal, Bradley, & Alderfer, 2013; Zegaczewski et al., 2016). Other factors which can contribute to poorer outcomes include lower social support, income, race, family functioning, and shorter time since diagnosis (Long et al., 2018). Future research would benefit from unpacking these further in order to identify those most at risk so that supports can be developed to meet these needs (Patterson, Millar, et al., 2011). To clarify the mixed findings, it is important to have consistency within the designs and to incorporate more longitudinal work investigating the mechanisms and moderators of adjustment to deepen the understanding (Houtzager et al., 1999). As a result, the timing and specific targets of interventions and supports will be better informed (Long et al., 2018).

Information and Communication Needs

Communication involves the process of information-giving and consists of components of support and feelings (Kennedy & Lloyd-Williams, 2009). Siblings consistently report these two needs as unmet (Houtzager et al., 1999; Kaplan et al., 2013; Long, Marsland, Wright, & Hinds, 2015; Nolbris, Enskär, & Hellström, 2007; Patterson, Pearce, et al., 2011; Porteous et al., 2018; Van Schoors et al., 2019; Yu & Bang, 2015). Without disclosing information through communication within the family, siblings are at greater risk of high anxiety and worry (Kaplan et al., 2013; Nolbris et al., 2007). As Kaplan et al., (2013) discussed, approximately 77% of siblings in the study thought the worst when told

about the diagnosis, due to a lack of understanding and communication. Greater attention needs to be paid to informing and supporting this group so that distress can be ameliorated (Kaplan et al., 2013).

Information also involves being told what changes to expect, information on coping, where to find support, and others being informed and aware (Porteous et al., 2018). In a study investigating the health-related quality of life (HRQOL) of 8 to 18-year-old Japanese siblings, it was discovered that due to the initial chaos post-diagnosis, siblings required information about expected family changes early on (Kobayashi, Hayakawa, & Hohashi, 2015). In order to facilitate adaptation. This mixed methods study utilised questionnaires to investigate the HRQOL and semi-structured interviews to investigate the experiences of the siblings and family relationships. Results revealed that although HRQOL was at a healthy level, it was still lower than controls (Kobayashi et al., 2015). By providing information and allowing involvement early on, this will help improve the QOL of siblings. Although the study does provide useful insights into the impact that sibling cancer has, answers may be slightly distorted due to being interviewed post-treatment, not during the illness where the impact may be more noticeable. Nonetheless, this study shows that there are lingering negative effects which highlight information-sharing as a continuous process, even after treatment has concluded (Long et al., 2018).

Information and communication is not the sole responsibility of the family; all who interact with the sibling have a role to communicate effectively. Though the family is the primary source of information (Van Schoors et al., 2019), there are others, especially within the school context (Alderfer & Hodges, 2010). If staff and peers are made aware of and are informed about the situation, siblings were shown to feel more able to open up (Porteous et al., 2018). Without, siblings were found to be more susceptible to receiving inappropriate responses, and sometimes even bullying. Through family-school partnerships, negative

outcomes resulting from these responses can be addressed, with resilience and mental health being nurtured (Alderfer & Hodges, 2010). This is especially so if the parents are emotionally or physically unavailable due to illness-related demands and distress (Alderfer & Kazak, 2006). Through providing teaching personnel with adequate information, they will be better able to attend to the needs of the siblings and, consequently, foster their academic success (Alderfer & Hodges, 2010).

Obtaining the experiences of siblings from their perspective is the first step to understanding what they need. Long et al., (2018) investigated this via one-on-one interviews utilising open-ended questions. For example, "Tell me what it is like to have a brother or sister who has cancer" and asking them how they cope. Similar to other studies (Long et al., 2018; Nolbris, Abrahamsson, Hellström, Olofsson, & Enskär, 2010; Porteous et al., 2018; Zegaczewski et al., 2016), siblings experienced a variety of emotions, including posttraumatic stress, anxiety, guilt, and jealousy (Long, Marsland, et al., 2015). It was concluded that these were a result of lack of communication, understanding, and concern with their sibling's illness. The younger they were and/or as the illness got worse, these were intensified due to poor understanding of the illness. Even receiving just the basics, they showed improvements in coping (Long, Marsland, et al., 2015). It is important that parents and health professionals are aware of the changing needs of siblings during this process; their need to be informed, updated, and supported. Due to a more heterogeneous sample of more males than past research, it shows that needs and experiences are consistent across genders.

Support Needs

Social support is the perception one has of being cared for, valued, and esteemed by those in their social network. It is shown to aid in and buffer an individual from adverse, stressful situations (Alderfer & Kazak, 2006). When siblings receive support, their ability to cope is enhanced (Zegaczewski et al., 2016). As research shows, siblings display high levels

of isolation from their families and others (Zegaczewski et al., 2016), due to the changes in relationships, attention on the ill child, changes in family dynamics, and increased responsibilities (Wilkins & Woodgate, 2005). Because of these factors, the need for social support becomes more prominent in the lives of siblings (Wilkins & Woodgate, 2005; Zegaczewski et al., 2016).

A recent meta-analysis showed that the need for social support is strong across findings, especially due to displaying cancer-related posttraumatic symptoms, poorer academic functioning, and more absenteeism (Long et al., 2018). Adolescents showed an even higher need for social support than their younger counterparts due to their developmental stage (Zegaczewski et al., 2016). Through provision of social support, the poor outcomes relating to school, mental health, and physical health are likely to decrease due to having an outlet where the siblings feel supported and have their experience 'normalised' (Long et al., 2018). Yet, research shows that there are risk factors and barriers which may hinder the accessibility or quality of these supports (Hamama et al., 2008; Long et al., 2018). These include poor family functioning, non-white race, shorter time since diagnosis, role overload (i.e. more responsibilities), and lower income. Notwithstanding, there is inconsistency amongst research of differing support needs based on age and gender differences (Davey et al., 2011; McDonald et al., 2015).

Research which has investigated adolescent needs indicate that older siblings require a greater level of peer support due to increased independence and need for companionship (Silver & Silver, 2013). This is more prevalent within Western cultures. As Alderfer and Hodges (2010) discovered, significant associations are shown between social support and improvements in emotional, behavioural, and academic functioning. These results were obtained through asking siblings to describe their perceptions of the amount of social support received and its importance across different contexts, alongside completed psychometric

measures. Specifically, teacher-based support was associated with better academic performance and less behavioural issues (Alderfer & Hodges, 2010). Support from classmates and other school personnel was associated with fewer symptoms of depression and isolation, less behavioural issues, and better social and academic skills within the classroom. Overall, school-based supports are just as important and relevant, if not more so, than parent and professionals due to associations displaying improvements across all areas of development (Alderfer & Hodges, 2010). This is particularly so as children and adolescents spend more time at school than at home. While the family is the primary source of support early on, due to disruptions experienced within this system and the changes in age, external sources become more valuable and significant.

One way to achieve effective school-based support is through partnership between family and school. Through communication with school personnel, better care and awareness will be provided for the sibling, with more appropriate responses to situational factors impeding the sibling's ability to function (Alderfer & Hodges, 2010). Additionally, classroom environments will be better equipped to meet the academic and emotional needs of siblings through the provision of counsellors, extra time for schoolwork, and breaks if they become overwhelmed. In turn this will reduce the burden for families as the school will become a safe space for siblings to turn to outside of the home and to maintain some normalcy (Alderfer & Hodges, 2010). Awareness, understanding, and support from parents, professionals, peers, and teachers also provides opportunities for open discussion from the siblings (Alderfer & Hodges, 2010; Alderfer & Kazak, 2006; Yang, Mu, Sheng, Chen, & Hung, 2016).

Support is both practical and emotional; access to social activities (Porteous et al., 2018), professional help (Patterson, Millar, et al., 2011), and opportunities to open up (Porteous et al., 2018). Without, siblings are at a greater risk of poorer psychosocial and academic outcomes as a result of stress and intense feelings (e.g. anxiety, guilt, jealousy).

Through being a part of a support group, these feelings may be normalised due to the knowledge that others also experience these (Wilkins & Woodgate, 2005). Siblings are in a vulnerable position due to a greater focus on the sick child and a lack of support. They are at a greater risk of psychosocial late effects, including posttraumatic symptoms, depression, and anxiety (D'Urso et al., 2017). Nevertheless, the past decade has seen a change in the standard of care for siblings within American pediatric oncology due to the increased awareness of their experiences (Gerhardt et al., 2015). Due to the psychosocial risk siblings face, the standard of care states that parents and professionals should be aware of ways to anticipate and meet their needs. As much of the research has shown (Zegaczewski et al., 2016), for many years professionals have often overlooked this group, which has been one of the main barriers to obtaining access to professional and social support for siblings. Within Aotearoa, this information is even more lacking.

Only one known study has been published within NZ which has investigated the needs and experiences of siblings (Porteous et al., 2018). With New Zealand having only two treatment centres, and with many families having to travel quite far to get to them, everyday family functioning can suffer great disruption. Authors asked siblings of their earliest memories of the experience, coping strategies employed, and advice to give to parents and professionals about what would be helpful. Six themes were formulated, including stress and distress, coping, feeling involved, “I wasn’t anyone’s priority”, connection and disconnection, feeling involved, and “it’s not all negative” (Porteous et al., 2018). Within these, other contributing stressors were reported. The majority reported intense feelings of isolation and lack of support; notably when the family had to travel far for treatment. Interestingly, when asked about what advice they would give to professionals, they reported struggling to express these feelings, with this being out of a lack of understanding from others. To combat this, awareness of siblings and provision of supports is crucial for their

well-being and ability to cope. In line with research on offspring (Davey et al., 2011; Maynard et al., 2013), groups of other siblings going through a similar experience or who have faced some hardship was reported as valuable to the siblings indicating the need for relatability due to genuine empathy and connection (Porteous et al., 2018). Based on these findings, it was concluded that siblings require support throughout all stages of the illness.

Being a part of a support group was shown to improve mood, behaviour, and schoolwork (Alderfer & Hodges, 2010). By utilising information on what is needed in conjunction with what works, researchers and health professionals are better equipped to develop and implement evidence-based supports for best practice. In addition, through partnerships between the family and school, siblings have access to further supports.

Evaluation of Supports and Resources

Current resources and support services exist like the SCNI (Patterson, Millar, et al., 2011), Camp Kesem for children (Silver & Silver, 2013), and *SuperSibs!* (Long, Goldish, et al., 2015). Internationally, resources and support services are shown to have high success rates, yet the need for support and information is still going unmet (Long et al., 2018). Indicating that accessibility to and awareness of them needs to increase.

Supports

Comparative to other countries, New Zealand lacks in resources and supports. With high rates of childhood cancer within NZ (Ballantine & NZCCR Working Group, 2017) and the distance some families have to travel (Porteous et al., 2018), demand is high for more accessible, generalisable support. Pre-existing programmes are run through organisations such as the Child Cancer Foundation and Leukaemia and Blood Cancer NZ, such as *Keeping in Touch* and *Kids Club*. The programme *Keeping in Touch* aims to reduce isolation, increase education, and provide an escape for siblings and parents of cancer patients. Support groups and camps are provided to enable them to connect, communicate, and find strength from

shared experiences. There are 22 branches nationwide, comprising of parents, caregivers, and volunteers who host social activities, offer shared experiences, and provide mutual support. For younger children between 5 to 12 years, a programme called *Kids Club* is offered. Facilitated by a Creative Expressive Therapist who runs activities and provides a supportive space for them to discuss their feelings, they are supported throughout the course of their sibling's illness.

Both New Zealand and Australia offer *Camp Quality* to 0 to 13-year-olds, providing them with life skills and strengthening their and their family's wellbeing to enhance coping. This is achieved through the implementation of programmes and services which are based on positive psychology principles. Laughter and optimism are seen as essential to help them cope and thrive, and they strive to achieve this. They believe that every young person has the opportunity to thrive. However, this is only for set period of time. Many siblings require support throughout the entirety of the illness (Porteous et al., 2018).

Within much of the literature external support is crucial (Davey et al., 2011; Long et al., 2018), particularly if and when the parents are not able to attend to and meet the needs of the children (Huang et al., 2014). Across the literature, one frequently discussed service is *SuperSibs!* (Alderfer & Hodges, 2010; Kaplan et al., 2013; Long, Marsland, et al., 2015). It provides support, care, and comfort for 4 to 18-year-old siblings and is part of one of the leading funders of pediatric oncology research across America and Canada. Families and siblings are equipped with toolkits that consist of age-appropriate information. The programme runs throughout their experience, even when their brother or sister has finished treatment. They then become a member of the Sibling Ambassador Programme where they are encouraged to open up about their experiences with other siblings.

Professional support such as counsellors is also a beneficial source for siblings to utilise, especially for adolescents who are shown to struggle to discuss their experiences and

the intense feelings they may experience (Long, Marsland, et al., 2015; McDonald et al., 2016). CancerCare in the United States is a national organisation which provides professional support services free of charge to anyone affected by cancer (e.g. counselling and support groups). By accessing the website, cancercare.org/services, individuals are offered a variety of supports which they can access. However, for younger children, many of these are in-person supports. If the parents are not aware of the sibling's needs nor have the ability to access these, then the sibling is still at a disadvantage.

Information Resources

Siblings require adequate information regarding the illness, what to expect, and be provided with opportunities to open up (Long et al., 2018; Van Schoors et al., 2019). Resources which incorporate this by normalising their feelings and supplying them with key information will enable them to feel more prepared and minimise any anxiety or depression. Within and outside New Zealand these still lack in scope, depth, and quantity.

Many organisations provide books, pamphlets, and booklets in digital and hard copies. Even with the many organisations such as CanTeen Australia, Alex's Lemonade Stand Foundation, and the National Cancer Institute in America, like much of the research (Houtzager et al., 1999), these resources are targeted towards the patient. New Zealand has a few resources aimed at siblings who are much younger and only a couple for older siblings. For the younger children, the resources focus on two cancer types (leukaemia and blood cancer) (Leukaemia and Blood Cancer NZ, 2015). For older children, the information is more generalised and covers a variety of topics including emotions, common questions, and terms and definitions (Child Cancer Foundation, 2011).

CanTeen Australia has 4 resources tailored to siblings and even their friends (Canteen Australia, 2014). Informed peers are shown to display more appropriate, supportive responses, which decrease feelings of loneliness experienced by siblings (Alderfer & Hodges,

2010; Porteous et al., 2018; Yu & Bang, 2015). However, as aforementioned, awareness of and access to these resources is crucial for them to have an impact, as well as being age-appropriate and for all ages. Due to the varying information needs, resources which are designed should consider these points. In addition, multiple resources on the website supply information for all family members, including during bereavement (Canteen Australia, 2014). The resources cover understanding the illness, coping, resources, and supports.

The biggest limitation of the lack of research available for a New Zealand population is that there is little know and understood about the needs of children within this context.

Conclusion.

The published studies which have been discussed within this chapter show that needs are still unmet, with the siblings and children of cancer patients showing high levels of distress and disruption. This is heightened without proper, age-appropriate information and support (Murray, 1999). Even though there are resources and supports, they are lacking in scope, generalisability, and accessibility, specifically within New Zealand/Aotearoa.

Earlier research tended to be heavily focused on the patients and their parents or spouses, with a shift in the last two decades towards the siblings or children (Patterson et al., 2017). The findings collectively show that these individuals are at risk of poorer outcomes, especially within the school if support and proper communication is not provided (Chowns, 2013). Additionally, as the research shows, there are differences in the amount and type of information and support that is provided, depending on the age of the child (Ellis et al., 2017). Gender has also been shown to reflect differences; girls, if their mother has breast cancer, want more information about future tests (Kennedy & Lloyd-Williams, 2008).

Most of the research has been done in other countries such as America and Australia, with only one published study and a Master's thesis conducted in New Zealand (Lamb, 2015; Porteous et al., 2018). This is problematic due to the high, and increasing, rates of cancer,

especially those who are over the age of 25 years (Ballantine & NZCCR Working Group, 2017). Without having a firm understanding of the impact of parental or sibling cancer on the children or siblings of these individuals through a New Zealand lens, they will continue to be overlooked and be at a greater risk of poor outcomes.

Although the two New Zealand studies by Lamb (2015) and Porteous et al., (2018) contribute to this area using a qualitative approach, they are limited in depth as neither utilised a phenomenological approach, nor did they investigate the impact of parental cancer. The research refers to cancer and the process as an experience (Murray, 1998), which emphasises the need for research to ask these young people about their own experience and perspectives. This is something which phenomenology aims to do, by reflecting upon each individual's lived experience (Lopez & Willis, 2004; Van Manen, 2016).

Regarding these points, this study aims to investigate the lived experience of children whose parent or sibling is living with cancer. This will further the understanding of the support and communication needs for this group. The hope is that this information will then aid in gathering an in-depth appreciation of the gaps within this area for what is lacking, ways to improve these so that the needs are met, and development of resources and supports to meet these needs. The aim is for this to be achieved in a culturally sensitive and age-appropriate way.

Chapter 3 – Methodology

"Most people do not listen with the intent to understand; they listen with the intent to reply".

(Stephen R. Covey).

The purpose of this chapter is to discuss the selected methodology for this study by providing an overview of phenomenology and the school which has been utilised for the current study. This includes a brief outline of research in human science from a qualitative approach, discussion of the history and background of phenomenology, the two schools within phenomenology, how analysis and write-up is conducted, and the methodological rigour utilised.

Research in Human Science

In most fields of research, there are three main approaches to a study design: qualitative, quantitative, and mixed methods. The former is a more recent approach, the latter is still developing and progressing in social and human science, and the quantitative approach is one that is predominantly seen in this area of research (Creswell & Creswell, 2017). With all approaches, it is important to consider the philosophical underpinnings, general procedures of research which are termed *strategies of inquiry*, and the procedures (methods) of obtaining and analysing the data (Creswell & Creswell, 2017). Each of the three approaches answer these in different ways.

The Qualitative Approach

In qualitative research, researchers are usually concerned with the meaning of things; how an individual makes sense of their world and how they experience things (Willig, 2013). Qualitative researchers aim to understand what a certain experience is like and how people cope. This approach is more concerned with "the quality and texture of experience, rather than with the identification of cause-effect relationships" (Willig, 2013, p. 9). There are no predictions or pre-conceived variables, as this would hinder obtaining the voice of the

participant; qualitative research is to explain, not to predict (Willig, 2013). The implementation of qualitative research is usually because there is a need to study a group/population of individuals, identify measurable variables, or to hear voices which have been otherwise silenced (Creswell & Poth, 2017).

Within this approach, there are two meanings: 'big Q' pertains to open-ended, inductive methodologies which are concerned with exploring meaning and theory generation, whereas the 'little q' pertains to the integration of non-numerical data collection procedures into hypothetico-deductive research designs. The former is more interested in gaining new insights into how something is experienced or meaning is perceived by an individual (Willig, 2013). This approach is utilised for many other reasons, such as when we need a deeper understanding of a phenomena or issue, to empower individuals to share their stories, make their voices heard, and to minimise the power relationship which is usually found between the researcher and the participant (Creswell & Poth, 2017). To undertake this type of research, it requires time, dedication, and resources due to rapport building with participants, data collection, and getting a better understanding from an insider's perspective (Creswell & Poth, 2017).

Due to the limited amount of research available on information and support needs from the perspective of children and siblings of cancer patients, a qualitative approach was the most fitting and appropriate choice. This is because it allows the researcher to carry out interviews in a naturalistic setting and ask the participants about their experiences and perspectives are of having a parent or sibling living with cancer. It also allows the researcher to ascertain views on what needs are unmet and what could help/be improved upon in the future. This is most likely to be achieved through the open-ended and casual nature of one-on-one interviews with participants being able to answer as much and as in-depth as they would like, or in a focus group whereby participants will be in a room with 4 to 5 others. The

data is collected and analysed via means of both audio recording and note-taking, which allows for the generation of a substantial amount of in-depth, complete information, as well as the ability to go back over the recordings and notes to identify any themes that may have been missed.

Overview

Phenomenology is a qualitative approach to studying the subjective human experience, aiming to understand people and their meanings and interactions with the world (Lopez & Willis, 2004). It aims to examine the subjective human experience through the traditional data collection approach of in-depth, qualitative interviews (Lopez & Willis, 2004). Other ways of gathering information can be through observations, video-taping, and even written narratives (Murray, 1998). Through the use of in-depth interviews, this enables the researcher to get a better insight and understanding of the experiences of an individual. This is because the output is a narrative account of their knowledge and experiences pertaining to a particular topic (Lopez & Willis, 2004). This account then provides a description of the subjective, lived experiences of the individual, which the researcher then analyses to produce the findings. From these, they develop detailed and rich descriptions of the participant's lived experiences and the meanings associated with them (Murray, 1998).

From a phenomenological point of view, to carry out research is always to question the way an individual experiences the world; to want to know the world in relation to the way we live as humans. Knowing the world is to be in the world in a particular way. Therefore, the act of researching (questioning, investigating, theorising) is the intentional act of immersing ourselves in the world, to become more fully a part of it; aids in our understanding (Van Manen, 1990). By investigating the lived experience of multiple informants, the researcher describes what all participants share as they experience the phenomenon and this is then reduced to a description of the general essence (Creswell, 2007); the essential nature

or true being of something (Van Manen, 1990). Phenomenology aims at asking what a particular experience is like, the way we immediately experience something pre-reflectively, paying particular attention to the details, and somewhat trivial aspects, of day-to-day life (Miles, Chapman, & Francis, 2015).

One of the challenges in qualitative designs is the absence of a link between the method employed and a clear statement of the philosophy which underlies it that guides the method (Lopez & Willis, 2004). In phenomenology especially, the findings generated will be dependent upon the philosophical approach used (Lopez & Willis, 2004). In phenomenology, there are two main schools/approaches, which include descriptive (eidetic) phenomenology and interpretative (hermeneutic) phenomenology. The difference is that the former describes a phenomenon separate from the context in which it is situated, whereas the latter aims to describe the *meaning* of a phenomenon and appreciate the context which shapes it (Bynum & Varpio, 2018). Interpretive phenomenology focuses on the *lived experience* (Bynum & Varpio, 2018).

The lack of information and research on the experiences and perspectives of a child or sibling who has a close family member living with cancer led to the development of the research question. This also facilitated the utilisation of an interpretative phenomenology design, as this design was considered as the best choice to enable the voices of the participants to be heard and the data to be a true reflection of their story and experiences. Therefore this allows for a deeper understanding into the lives and experiences of these children and siblings.

Background

Although the philosophy of phenomenology originates from and is first formally announced in the work of Husserl and his former student, Heidegger (Miles et al., 2015), some of its early appearances can be found in the work of people such as Immanuel Kant,

Ernst Mach, and Georg Wilhelm Friedrich Hegel (Moran, 2002). Husserl believed that phenomenological practice required a 'bracketing' (setting aside of preconceived ideas) of the day-to-day attitude and intentional acts which exist until the practitioner is led back, reduced, to the domain of pure consciousness *(transcendental subjectivity)*, and without this, genuine phenomenological understanding would not be possible (Moran, 2002). In other words, looking at the essences and themes of a particular experience, and then coming back to how that person experiences and perceives it themselves so that we can obtain a better understanding of the nature of that particular event or experience; rather than the researcher allowing their experiences to describe it (Moran, 2002). This is a way for the experience to be perceived with 'fresh eyes', as if it is the first time (Creswell, 2007).

It is important to note that it does not prescribe to one particular method, theory, or even philosophy; which some interpreters have done (Moran, 2002). Each philosopher is different in their interests, interpretations of phenomenological issues, and their understanding of the applications of the method. Martin Heidegger, one of Husserl's former students, stated that there is not one type of phenomenology (Moran, 2002). Philosophy is diverse and follows the matters themselves, which Heidegger believed: phenomenology identified with the essence of philosophy, being diverse itself in its approach. The way in which he attended to the things – essences – themselves closely followed Hans-Georg Gadamer (Moran, 2002): through the use of an interpretative process using language, it leads to the knowledge and discovery of a phenomena (Miles et al., 2015). In simple terms, the essences of an experience can be found within language – speech.

Due to phenomenology having deep roots in philosophy, it is important to understand the theoretical implications of carrying out such research (Van Manen, 1990). Similarly, the research findings produced will depend on which approach is used (Lopez & Willis, 2004). Phenomenology stresses getting to the truth of matters (describing phenomena) in the

broadest sense of however it appears in the consciousness of an individual (Moran, 2002); *their* lived experience. The first step is to attempt to avoid all misconstructions and previous notions that an individual has – especially a researcher. This is so that explanations for the phenomena are not imposed prior to obtaining an understanding of it from within (Moran, 2002). Some of the philosophical assumptions rest on shared aspects: (a) it is the study of the lived experience of an individual, (b) lived experiences are viewed as conscious, and (c) the development of the description of the essences – they are not analyses or explanations (Creswell, 2007; Van Manen, 1990).

There are four philosophical perspectives within phenomenology, and it is important that these are discussed and acknowledged when carrying out this type of research (Creswell, 2007). These include: (1) phenomenology returns to the traditional philosophical task of searching for wisdom, (2) all presuppositions/judgements of the real, ”natural attitude” are suspended until a more definite basis has been founded (obtaining an understanding from the perspective of the individual), (3) consciousness is intentional in that it is always directed towards an object, with that object’s reality based on the individual’s consciousness (awareness) of it, and (4) there is a rejection of the subject-object contrast, which follows on from the above. An object’s reality is only perceived by the individual in relation to their meaning of an experience (Creswell, 2007).

Two Schools of Phenomenology

Within phenomenology, there are two schools of thought; the first being the eidetic, descriptive approach of Husserl (the founder), and the other being the interpretative approach of his former student, Heidegger (the transformer) (Moran, 2002). The latter is a combination of both description and interpretation, focusing on the meaning of being (ontology). Both schools within phenomenology aim at getting an understanding of the lived experience of an individual, however, the difference is that the descriptive approach looks at the

concepts/things (essences) themselves to provide the meaning. The interpretative approach is a combination of description and interpretation; the meaning of being. More specifically, Heidegger asserts that reflection is a crucial part of hermeneutics, and that in order to achieve interpretation, the researcher needs to purposely reflect (Miles et al., 2015); occurs in all encounters, which the social context influences.

When it comes to phenomenology, not one philosophy is better than the other. The school used depends on the question being asked, and in turn, the type of approach used will impact the findings generated (Lopez & Willis, 2004). There are two schools or methods within phenomenology: descriptive (eidetic) and interpretive (hermeneutic) phenomenology (Lopez & Willis, 2004). Although both are a type of interpreting, according to Gadamer (1986), there are two different types. The first is that it points *to* something (revealing), and the other is pointing *out* the meaning of something already known (Gadamer & Hans-Georg, 1986). In regard to phenomenology, a text is descriptive due to its naming of something, and this points to something which is then interpreted; the interpretive/hermeneutic phenomenological approach (Van Manen, 1990).

This next sub-section outlines and briefly describes the two different schools of thinking, with an emphasis on the interpretive school as that is the chosen approach for this study. This is then followed by a rationale for the chosen approach.

Descriptive

Descriptive, or Husserlanian, phenomenology is a pure description of the lived experience of an individual (Van Manen, 1990); an immediate description of the lifeworld. A description of lived experience is pointing out the experience of the individual in its simplest form: it shows the lived experience of a person (Van Manen, 1990). The procedure of this approach starts with identifying a phenomenon to study, followed by bracketing, or setting aside the knowledge that the researcher already has of the experience or phenomenon,

allowing them to look at it with 'fresh eyes' (Creswell, 2007). The next step involves collecting data from multiple individuals who have experienced the selected phenomenon, which is then analysed by the researcher to be reduced to significant statements or quotes, which are then turned into themes. Following this, a *textural description* of the participant's experiences is then developed (what they experienced), and then a *structural description* which is how they experienced it in relation to the conditions, context, or situations. Both of these descriptions then reveal the overall essence, or the true nature, of the experience/phenomenon (Creswell, 2007).

Interpretive

Interpretive, or Hermeneutic, phenomenology is an interpretation of experience via some 'text' or other symbol (Van Manen, 1990); usually through analysis of conversations to retrieve themes. The meaning of the lived experience is usually concealed or hidden, and the goal of the phenomenological approach is to discover that through interviews and analysis of these (Van Manen, 1990). In contrast to the descriptive approach, the interpretive approach aims at discovering the *meaning* of the lived experience; what it means for that individual and how they perceive the experience and world around them. Max van Manen (1990) asserts that there is not a particular structure to the process of carrying out interpretive phenomenology, but rather it is a dynamic interaction between six research activities. This involves the researcher turning to a phenomenon which interests them, and in the process of doing so, they reflect on the essential themes: what constitutes the essence/description of this lived experience (Creswell, 2007). A description is written by the researcher, whilst preserving a strong relation to the topic being investigated and balancing each part of the writing to the whole. Not only does the researcher write a description of the phenomenon, but they also are involved in a process of interpreting the meaning of the lived experiences of the participant; the researcher mediates between different meanings (Creswell, 2007; Van Manen, 1990).

Process of Analysis

Due to the type of data collection employed such as writing, audio, and visual, analysis is done in an idiographic manner, whereby each one produced is looked at with an intensive and detailed engagement by the researcher (Willig, 2013). This is because the central component of this type of analysis is the meaning. The aim of the researcher is to attempt to understand the complexity and the content of those meanings (Smith & Osborn, 2004). There are usually three stages which are involved in analysing this type of data. The first stage involves going over the data (reading or listening) multiple times, taking down any initial thoughts or observations, with the notes being quite unfocused (Willig, 2013). The next stage includes identifying and labelling any themes which characterise each part of the text; the themes tend to capture something to do with the essential nature of what is expressed in the text. Finally, the third stage, attempts to introduce the structure of the text; listing the themes and thinking about them in relation to one another (Willig, 2013). The themes may naturally form clusters, or over-arching themes, which consist of similar subthemes (e.g. going to school and the relationship with the mother come under a "childhood" cluster). Then a summary table follows consisting of the structured themes alongside quotations which illustrate each theme. This is typically done when integrating each case and finding common or similar themes produced by each experience and then combining into one.

Due to being a subjective approach to research, data interpretation should be done with an awareness of the researcher's own interpretative resources (Smith & Osborn, 2004). It is important that they are constantly checking their understanding against what was actually said by the participant. Thus, data interpretation within the phenomenological school is done cautiously and with detail. Depending on the number of cases, the researcher can either use the first case as a basis for all others, or start from scratch on each one (Smith & Osborn, 2004). The latter is predominantly used when the number of cases is small. Regardless of which approach is used, it is important that the researcher discerns repeating patterns as well

as recognising new issues whilst working through each one. The aim is to respect similarities and differences amongst the participants' data (Smith & Osborn, 2004). Once every transcript has been analysed, a final table of superordinate themes is established. This is one of the most challenging parts of analysis, as deciding upon which themes to use requires the researcher to prioritise the data and reduce them (Smith & Osborn, 2004). There are many factors to consider when selecting the superordinate themes: how the richness of each passage highlights the themes, how the theme helps to emphasise other aspects of the transcript, and the frequency.

Writing Up

When writing up the results, each theme is introduced followed by a discussion of its manifestations alongside quotations by participants which are used to illustrate them (Willig, 2013). Relationships between the themes are also used and discussed within the write-up. It is important during this stage to make it clear that the comments from the participants and the researcher's interpretations are different; therefore, reflexivity issues should be discussed (Willig, 2013). During the write up, similar to other methodologies, the themes of the current study are discussed and how they relate to the existing literature in that area.

During the analysis process, the transcript is read multiple times, with the left-hand side of the page being used for annotations of interesting or significant aspects of what has been said (Smith & Osborn, 2004). During the first stage of analysis, the transcript is typically read and reread closely so that the researcher is as familiar with the transcript as possible, and the benefits are that there are no rules as to what is commented on; close to a "free textual analysis" (Smith & Osborn, 2002, p. 67). Additionally, comments vary in terms of depth and detail, with some warranting more commentary, whereas others don't require as much. Some comments will attempt to summarise or paraphrase, others bring associations or connections, and still others will be preliminary interpretations (Smith & Osborn, 2004). This

is done for the whole of the transcript, then the researcher/transcriber goes back to the start of the transcript and documents emerging theme titles.

Rationale

Phenomenology was chosen for this study as it allowed the researcher to obtain a better understanding of the experiences of young people who have a family member living with cancer. More specifically, interpretative phenomenology was selected as it explores in detail how a person makes sense of their world and the meaning that certain experiences have for them. This is because as the researcher I wanted to obtain a better understanding of the experience of having a parent or sibling living with cancer and how they perceive it. This is so that we can obtain better knowledge on the needs of the children and siblings within a New Zealand/Aotearoa context. This design provides young people with a voice to be heard.

Methodological Rigour

Methodological rigour consists of criteria which ensure that the methodology employed within a study is accountable, systematic, and high-quality (De Witt & Ploeg, 2006). Within human science research, it is deemed rigorous when it is morally strong (Van Manen, 1990). Within Interpretative Phenomenological Analysis (IPA), this rigour and commitment is observed from start to finish throughout the whole analytical process (Shinebourne, 2011).

There are four factors outlined by Sandelowski (1986) for ensuring rigour. The first criterion is truth value. Quantitative research typically assesses this through evaluating how well threats to internal validity are managed, in addition to the validity of the tests and instruments. This is when the researcher can show that nothing else can account for the results such as subject selection, history and maturation, etcetera (Sandelowski, 1986). However, within qualitative research, truth is a more elusive goal, because the results are typically more subjective. They rely on the perceived experience or phenomena as an

individual lives it; based on the participant's perception, not on a test (Sandelowski, 1986). Therefore, the criterion within qualitative research is argued to be credibility. The criterion of credibility is when descriptions or interpretations are faithful to those who have experienced the phenomena being studied. There is a relatability component, whereby those who have experienced it can immediately recognise that experience as their own when they read it (Sandelowski, 1986). Additionally, when others (e.g. researchers, readers) can recognise the experience in everyday life by reading about it, and when descriptions match or closely follow what the participants said, then a study is deemed as credible. A threat to this criterion is the closeness of relationship between the researcher and the participant. This can happen when the researcher's own experiences become too entangled with that of the subjects, therefore preventing meaningful descriptions or interpretations of the data (Sandelowski, 1986). As stated, "A useful way to view researchers in qualitative inquiry is *as subjects* in their own studies" (Sandelowski, 1986, p.30). Through describing their own experiences in relation to the participants, this enhances the credibility of the research.

The next criterion for qualitative studies is applicability. Quantitative research refers to this as how well threats to external validity have been managed to ensure generalisability and representativeness of the data (Sandelowski, 1986). This involves making sure that the test conditions match conditions of the real world closely. Although generalisability and representativeness are sought in qualitative research, there are less threats to external validity. This is due to emphasising the study of phenomena or experiences within their natural setting, with fewer controlling conditions. Therefore, the criterion which the applicability of qualitative research should be evaluated against is fittingness. When a study fits into a context outside the study situation and the audience can view the findings as meaningful and applicable to their own experiences, then the study meets this criterion. Additionally, the

findings, regardless of their presentation, fit the data from which they are derived from; they are well grounded in the life experiences studied and reflect all elements of them.

Consistency is the next factor and in quantitative research is measured by the criterion of reliability. This refers to the dependability, consistency, and stability of the test or testing procedure. A study is reliable when it yields the same results each time it, or a similar form of it is conducted on the same or comparable subjects and has internal consistency. This rests upon the assumption that replication is possible with no alterations to what is being studied; regularity to the human experience. However, qualitative research emphasises the uniqueness of human situations and the importance of experiences which are "not necessarily accessible to validation through the senses" (p.33). Because qualitative studies seek variations rather than identical repetition, this is why the criteria auditability is chosen to measure consistency. A study and its findings are audible when the trail of decisions made by the investigator can be clearly followed by another researcher, arriving at the same or comparable conclusions.

The final criterion is neutrality and it refers to freedom from bias in the process and product of the research. Objectivity is the criterion employed in quantitative research and is achieved when reliability and validity are established. The inherent goal of this criterion is that there should be a distance between the researcher and the participant, whilst data collection is maintained. The assumption is that there is something to be known and a knower, with the relationship characterised by separation and distance. Contact between them is controlled and mediated by protocol, theory, and instrumentation. Contrarily, qualitative research values subjectivity and the meaningfulness of the findings, achieved by decreasing the distance. Objectivity is argued to be a socially constructed phenomenon which produces the illusion of objectivity. There is nothing that can erase the fact that studying something changes it. A study and its findings reflect the investigator and the phenomenon studied. For

qualitative research, the criterion when it comes to neutrality is confirmability. It refers to the findings themselves, not to the stance of the researcher (i.e. objective versus subjective).

Conclusion

Phenomenology is one way of researching within human science through investigating the lived experience of individuals of a particular phenomenon. This is achieved via the utilisation of semi-structured interviews asking the individual about their experience and their perception of the phenomenon being studied. The two schools within phenomenology – interpretative and descriptive – both achieve this in different ways. The descriptive looks more at the concepts to provide meaning, whereas the interpretative looks at the meaning of being. For the purposes of the current study, interpretative phenomenology is employed as it allows for a deeper understanding of what it means to have a parent or sibling living with cancer and what they feel would be beneficial to them in terms of supports.

The following chapter discusses the steps taken to ensure that the current study is in line with interpretative phenomenology. In addition to the plan for recruitment and the obstacles and reality faced during this process.

Chapter 4 – Method

"A research method is only a way of investigating certain kinds of questions".

(Max van Manen, 1990).

Introduction

The most appropriate methodology for this research utilises a qualitative framework informed by Hermeneutic/Interpretative Phenomenology which focuses on the lived experience of people as they interact with their world and to understand this through the use of interviews, observations, and video-recording (Bynum & Varpio, 2018; Murray, 1998). This methodology was chosen to obtain a better understanding of the experiences and needs of siblings and children with a family member with cancer and find meaning within those experiences to create better information resources through detailed analysis.

The design of this study has been informed by Van Schoors et al., (2019) and Morris (2009) through the utilisation of IPA and semi-structured interviews. However, what makes this research design different, is the incorporation of focus groups, depending on the preferences of the young people. This is because the majority of recent research reports a high need for peer support groups, as these are shown to decrease feelings of isolation and encourage individuals to open up (Ellis et al., 2017; Huang et al., 2014). Once consent and assent forms have been completed by the participants and their parents, each interview or focus group will be recorded using a voice recorder. The recordings will be analysed verbatim and the researcher will closely follow the methodological rigour outlined above. The researcher will look for trends which emerge across all responses, and through this process, these will then be placed into meaningful categories, with overarching themes being investigated. During this process, pseudonyms will be used for each participant to maintain their confidentiality.

Method

Participants

Recruitment: This will be done through contact with Canteen, the Child Cancer Organisation, and the Cancer Society support groups, where invitations will be sent to those engaged in these services. In addition to flyers being placed within pediatric oncology wards. Information about the research project will be provided by these three organisations so that there is no coercion. Those who are interested in participating will be able to contact me for further information. Participants will be between the ages of 7- to 18-years-old and have either a parent or a sibling who have been diagnosed with cancer within the last 1-3 years. The sample size will include approximately 8-10 offspring and siblings. This is due to phenomenological studies typically consisting of a small sample size due to the nature of data collection and analysis (Creswell, 2007).

Prior to the commencement of the interviews, all participants will be provided with written and verbal information in regard to the study. In addition to consent forms if they are over the age of 16 years or an assent form if they are under 16 years; based on ethics recommendations. These forms include their permission to be audio recorded during the interviews to make sure that the data collected was reliable. Although written information was given to the families prior to the start of the study to obtain interest, they will be supplied with it again just before the study should they have any questions or concerns.

Criteria: The criteria inclusion for participants will be children and young adults between the ages of 7- to 19-years-old due to cognitive ability and maturity. Additionally, the participants will have either a parent or a sibling who have been diagnosed with cancer within the last 1-3 years and/or receiving treatment. This is because research suggests that time since diagnosis can impact the results (Maynard et al., 2013). If the focus-groups are conducted too close to the diagnosis, due to the ages of the children and siblings and the serious nature of the topic, this could be quite traumatic for the children. However, if they are conducted too long after

the diagnosis, research suggests that recalling their experiences may be less detailed (Maynard et al., 2013; Morris et al., 2016; Walczak et al., 2018).

Procedure: Previous literature shows that for IPA, the most commonly employed form is the conducting of one-on-one interviews (Willig, 2013). This is because they are compatible with many methods of data analysis and allows for rapport to built between the researcher/interviewer and the participant (Willig, 2013). By conducting a semi-structured interview with participants, it allows the researcher to enter the lifeworld of the participant, through enabling them to share their experience of the phenomenon more openly. Interviews will be done in an environment which is as comfortable and supportive for the participants as possible which will encourage engagement and openness with the interviewer. Times and settings for interviews will be organised in advance alongside Canteen and the Cancer Society via email or phone. Primary data collection will consist of interviews with approximately 8-10 participants and 4 parents, with all answers being recorded and transcribed. There will also be the choice of the participants being able to write down their answers or partake in a focus group.

As stated above, the participants will be given the choice out of three options: a one-on-one interview (with the addition of a family or friend if they would like), to be part of a focus group, or to write down the answers. Although interpretative phenomenology predominantly uses semi-structured interviews (Willig, 2013), due to much of the research showing that young people report a need for support from peers going through a similar situation (Davey et al., 2011; Porteous et al., 2018; Wilkins & Woodgate, 2005), the option for a focus group is given. Additionally, due to their age and developmental stage, by being in a group of peers, they may feel more comfortable sharing their experiences.

Interviews are the most commonly utilised form of data collection in qualitative studies, as it is compatible with multiple methods of data analysis (Willig, 2013). By doing

interviews, this will allow for a more intimate and warmer environment for the child or young person as it will enable rapport to be built, which will in turn help the participant in answering questions and elaborating. All participants will be given written consent and/or assent prior to interviews based on age and maturity, with children under the age of 16 years being required to obtain parental consent. All interviews will be recorded to ensure clarity when analysing the data. Any transcribers used in the process of data analysis will sign a Transcriber Confidentiality Agreement. Baking, tea, coffee, and water will be supplied and offered to the participants during the interviews as a thank you for their contribution, time, and participation.

Ethical Considerations

During both the planning and the execution of the current study, awareness was maintained of the serious nature of the illness and the distress that it can cause to young people and their families. Therefore, this study aimed to investigate the topic in both a sensitive and culturally sensitive way, taking into consideration the vulnerable nature of the participants. Ethics approval was obtained for this research by The University of Canterbury's Human Ethics Committee (Appendix A).

Throughout the discussion and development of the study, I was mindful of the potential upsetting nature of having a parent or sibling diagnosed with cancer and having treatment for this. When it came to the development and implementation of the questions, this was taken into consideration. Due to the utilisation of a phenomenological approach, interviews are non-invasive and the participants will be free to discuss what they feel is important, and are free to step out or stop answering so that levels of distress were kept to a minimum.

All participant information will be kept confidential throughout the entirety of the research. During the focus groups and interviews, name badges will be worn so that rapport

can be built between the researcher and the participants; helping to provide a warm and welcoming environment. No personal information relating to the participants will be used except ethnicity. In the information sheets the participants are informed of where the data will be kept, how it will be kept, and for how long (Appendices B-G). The participants are also given the opportunity to contact the researcher after the interviews if they have anything more to add or if they want to change or withdraw any information. They will also be offered a copy of the written report once finished.

At no point in the research will the participants be misinformed or deceived, nor will any information be withheld from them. Once complete, the participants will be sincerely thanked for their valuable contribution.

Questions

The structure of the focus-group will use a semi-structured interview technique, where there will be a few main questions and then prompting questions when required. The topics covered will include the experiences of each child, the support and information that they have found helpful and not so helpful, what they know about the illness, and what supports and information they would like to receive.

Intended Focus-Group Questions (examples):

1. Can you tell me about your experience of having a parent or sibling with cancer?
2. What support and information has been helpful?
3. What support and information would you like to receive?

Prompting questions or questions for clarification will be asked when required.

Recruitment: Plan

The plan was to contact the two cancer organisations in New Zealand: Cancer Society and Canteen. Through contacting the staff at these organisations via email and phone, I was able to discuss the aims of the study and what it was about, as well as arrange to meet in

person to further discuss. The study information was to then be sent out to potential participants by the organisation to see if there was any interest. This is so that there would be no coercion by the researcher; no conflict of interest. For those who were interested, they were then to be given the contact details of the researcher so that they could be further informed of what was involved and other details such as when and where the interviews would be held.

Recruitment: Reality

At the commencement of the thesis, I was in liaison with Canteen, discussing the research, what would be involved, and the recruitment process through face-to-face meetings and email. They were supportive of this research as they were concerned about a perceived lack of appropriate resources and support, and awareness of these. However, due to unforeseen circumstances, Canteen started closing offices due to financial reasons, and I was no longer able to work with them at the commencement of this study.

I expanded the scope of organisations that I contacted and was supported by participants recruited via the Cancer Society New Zealand and Sweet Louise. Sweet Louise is a foundation founded after Louise Perkins who passed away from incurable (metastatic) breast cancer and it aims at improving the quality of life for individuals in New Zealand who live with incurable breast cancer. Due to low numbers in interested families, focus groups were not utilised. Therefore, data collection was achieved through one-on-one interviews in the location of participants choosing. For two of the youngest participants, phone interviews were utilised as they lived a distance away from a main city.

The data was gathered via the means of semi-structured interviews guided by the main research question, “What are the experiences and information needs for youth who know someone with cancer?”. Through the use of semi-structured interviews, it allowed for a better exploration of the individual’s experiences through their own narratives due to

elaboration (Murray, 1998). The benefit of using this style of interview is that it allows the participant to elaborate further which in turn can help the interviewer understand better. Additionally, it allows for clarification of answers through further questioning, which can in turn ensure the validity of the participants answers.

Conclusion

Utilising the framework informed by IPA, cancer-based organisations were approached for the purposes of recruiting interested participants and their families. Once achieved, semi-structured interviews were employed to ask questions investigating the needs of children of cancer patients. Done in a sensitive manner and with ethics approval, participants shared their experiences of having a parent living with cancer and what they want to see more of pertaining to support and information.

The following chapter expands upon these interviews and the analysis, through discussing the results and interviews of each participant. Discussion will include each theme and subtheme which emerged throughout the analysis process and the examination of each one alongside appropriate excerpts from each participant.

Chapter 5 – Results

There is no courage without vulnerability.

Brené Brown

The purpose of the study was to explore the experiences of young people who had either a parent or a sibling living with cancer. This was in order to obtain a greater understanding of their information and support needs. The data gained from semi-structured interviews was analysed following the format outlined in chapter four.

Analysis

The data was analysed utilising the IPA process, through in-depth readings and re-readings of each transcript so that the researcher was familiar with what each participant said. Because of the broad nature of IPA, Smith and Osborn (2004) state that the first transcript can be used as the basis for all others, or the researcher can start from scratch with each one (p 72). For the purposes of this study and due to the small number of participants, the researcher chose to start from scratch with each one. When identifying themes, the overarching themes were discussed by all yet the subthemes were sometimes only specific to some participants.

During the reading and re-reading of each transcript, the researcher took note of any quotes which had depth and meaning to them, which were then further analysed. Any emotions, initial thoughts, and ideas were written for post-analysis purposes. From the initial analysis, the researcher went back through each transcript individually to write initial themes and subthemes, which were then further condensed and collated. This latter part was achieved by placing all four transcripts next to one another and seeing which themes and subthemes were most prevalent and consistent amongst the participants. Once this was done, they were placed within a table with the subthemes which corresponded to each one placed below them. There were a total of six themes which were revealed alongside seventeen subthemes post-analysis. These were then re-checked against the original transcripts to make sure that the

researcher's own interpretations did not deviate from the original data of the participants. Themes which emerged out of the analysis included Change, Support, Time, Communication, Every Child is Different, and Family Separation. Within these themes seventeen subthemes emerged (see Table 1) which described the experiences and the needs of the participants. In the following sections I will be elaborating upon these, using quotes from each participant to support.

Table 1.

Themes and Subthemes from Data Analysis.

Themes	**Subthemes**
Change	A New Normal
	It's Not All Bad
	Change with the Sick Parent
Support	Having the Choice
	External
	Having a Break
	Accessibility and Availability
	Emotional
Time	With the Sick Parent
	Helping Out
	The Process
	The Future
Communication	With School
	At the Start
	Open
	Having the Conversation
	The Positive
Every Child is Different	
Family Separation	

Change

Change emerged as a key theme. This involved emotional changes, changes in the physical appearance of the sick parent, a new normal within the family, and positive changes.

A New Normal.

Two of the participants expressed that life had changed substantially for them since their parent was diagnosed with cancer. As Rachel (aged 19) articulated, *"Quite, a change to, normal, life, I guess, before, yeah".* For her, all areas of life had changed a lot since her Mum was diagnosed with cancer and she appeared to be struggling with this news. I observed during the interview, Rachel was struggling with the changes that had ensued. This was evident in her struggle to elaborate upon what areas of life had changed for her, just that life was not *"normal"* like it once was. I noticed she did not talk about her mother's diagnosis nor did she use the word 'cancer', as if to protect herself from the reality of her situation. Huang et al., suggest changes could be increased responsibilities within the house, less socialising, and even becoming another caregiver. Research by Faulkner & Davey (2002) and Hagedoorn et al., (2011) also indicates that when a parent is diagnosed with cancer, the whole family may face many changes to daily life and they all have to adapt to a new normal.

For Daniel (aged 12), these changes were more specific, and he was more open about what he saw. When asked what had changed for him, Daniel shared that the *"cycle"* within the house had changed. This included the alteration in how and when things were done in the house. Daniel's examples were of times when he had been asked to do things around the house.

> *"he used to ask me to do stuff, I'd like get off my chair and then 20 minutes later do it. But now, like I'll get on and do this for him".*

Listening to Daniel, I noticed that there was a sense of urgency to complete tasks that his Dad had asked him to do. Daniel mentioned that prior to his Dad being diagnosed with cancer, he would take some time to do jobs required of him, whereas now he does it instantly and *"gets on"* with it. Daniel added that he let his Dad sleep in more and made cups of tea for

his parents. Doing such tasks may not be as noticeable to older children due to greater expectations and responsibilities that they already have, but for children who live at home and rely on the parents to take care of them, this change can be more salient as they are now stepping into more of a caregiver role. This is quite a common change across the literature for adolescents (Chowns, 2013; Kennedy & Lloyd-Williams, 2009; Phillips, 2015; Silver & Silver, 2013) (Huang et al., 2014). However, the experience of the participants in my research suggest that irrespective of age, added responsibilities can fall upon the oldest child within the family.

It's Not All Bad.

Although children have to adapt to changes in life when a parent receives a cancer diagnosis, it may not be a negative change. Finding positives can provide hope in a tough situation, which Daniel and Kaitlyn both touched upon. Throughout Daniel's interview, I noticed that he showed a high level of maturity through seeing both sides of the situation.

"There's like a good side to it and a bad side to it". (Daniel aged 12)

Maintaining a positive mindset and noticing the positive aspects can help children to cope better (Phillips, 2015). When Daniel talked of the good and bad aspects of his Dad's cancer, he spoke to the point, demonstrating that it was not all bad.

"like the bad side is that he's got cancer and that he, has these, mysteries, which have been uncovered. But like the good thing is that I get more time with him, coz he doesn't coach tennis as much". (Daniel).

For both him and his younger sister Kaitlyn (aged 9), they appeared to have found hope in his ability to return to doing the tasks he once was able to do. As Kaitlyn shared, the new drug that their Dad had been placed on had given her Dad *"a second chance at life"*. Throughout both of their interviews, the drug that their Dad was on was a focal point of discussion, emphasising the importance of it. The drug had provided a positive change for

their Dad, he started walking the dog and taking tennis lessons again. During this discussion, I noted the delight that they had found in these changes.

"He was actually was feeling way better, he could walk the dog, he could um he can do like everything basically, and now he still he's gotten like a few tennis lessons still in". (Kaitlyn aged 9)

"later he was like, wants to walk the dog around, he was like wants to help everybody, and I was like woah". (Daniel aged 12)

For them, this sense of normality returning was important and demonstrated improvement to how their parent had been at the start of his illness. Maintaining some normal aspects of daily life from pre-illness times can help children in finding positive aspects, alleviate some of the common stressors of the illness, and help the child to cope.

Physical Change Within the Parent.

This subtheme was a prominent concern for Jack (aged 19), who offered insight into this struggle by witnessing the physical changes his Mum went through and the impact this had on him.

"And I think the, one of the challenge- most challenging thing is actually, like being down here for of course most of the year and then for the small holidays that I may go back for, there may be like big changes in my Mum's health between that point and then, so it can be quite, I suppose, overwhelming".

Jack's tone of voice and his struggle to verbalise, alongside mentioning the physical change multiple times, suggested to me that it was a very noticeable change which he struggled with. In addition, he was living away from home, therefore the adjustment to these changes was more evident and appeared more sudden than perhaps they might have been if he was living at home, where the changes may have been more subtle. It was a shock for Jack. These changes can affect children who live at home, but it can have a far greater impact

upon those who live away. As reported in one study, a child moved back home from university due to the worries and fears that they had about their sick parent (Rodriguez et al., 2018). For Jack, living back at home was something that he desired as the changes would be a more gradual adjustment rather than a massive shock.

"I think for some people it definitely would help to not having that in your life all the time, but I think for me, it would work better if I did, in some ways."

"I think ultimately coz I, yeah it was pretty shocking just coming back at one point and seeing my Mum and she'd like, just was really struggling to walk and something". (Jack aged 19)

By mentioning that being home may work in some ways, it appeared to me that there was conflict between the positives of being home and not. Although the physical changes would not be as shocking and he would be able to help his Mum better, the reality of his Mum's cancer may settle in more. These excerpts highlight the impact the physical changes that a parent with cancer experiences has on their child, yet through better support and preparation, this may be alleviated.

Overwhelming.

Change in emotions can be overwhelming for many children, and all four participants experienced different negative emotions than they had before. As Jack (aged 19) shared,

"so it can be quite, I suppose, overwhelming to have to see that".

"prior to that I had a couple of, unfortunate life events and it leaves me, developing quite bad depression". (Jack aged 19).

Jack was very open when discussing his Mum's cancer and the impact that it had on him, discussing the shock of it all. During the interview, I observed how deeply his Mum's cancer had affected him through his struggle to verbalise how he felt and the difficulty he was experiencing in being able to fully process what he was feeling. In a study by Thastum et al.,

(2009), children and adolescents were shown to be susceptible to developing psychosocial problems, especially when there was an accumulation of negative events.

Daniel (aged 12) also shared experiencing depressive-like feelings at the start when his parents finally told him what was going on.

> *"But when you're like going through like a point where you're like hopeless. Like a point where you feel angry and sad at the same time. Like depression".*

In this excerpt Daniel displays the emotional struggle that a child may face when their parent is diagnosed with cancer; the anger of not being told straight away, the sadness of their parent being diagnosed with a very serious illness, and the hopelessness of not knowing what to do. Supporting these findings is the work of Thastum et al., (2008), which showed that latency-aged boys and adolescent girls are more likely to experience psychosocial issues such as depression, especially when it is their father who is diagnosed. Although Daniel does not have clinical depression, he likens how he feels to depression, thus emphasising the severity of his emotions.

Some parents choose not to tell their child straightaway or limit how much they tell them so they are not overwhelmed. As shared by Rachel's Mum:

> *"We haven't really tried to make it too big'a deal".* (Rachel's Mum)

She and her husband felt as though they were doing what was good for their children by not making a big fuss out of the illness, indicating that they were trying to protect their children by not overwhelming them with everything that was happening. However, withholding information or delaying telling their children of the diagnosis can lead to feelings of exclusion and anger. Jack and Daniel both reported feeling angry and annoyed towards their parents due to a lack of information.

> *"I got the impression that my parents had tried to maybe not tell me e-everything that's happening right at the moment just not overwhelm me or anything, which is fair*

enough as well, but I think it would be nice to have the option that if I wanted to find out that kinda stuff I could". (Jack, aged 19)

"But like at the start when I didn't get told, yeah. But I just let go". (Daniel, aged 12)

These excerpts highlight the importance of sharing the diagnosis and information with children and the effect that not doing so can have. As Jack indicated, he felt that his parents had tried not to tell him everything for protective reasons. However, being someone who liked to know as much as possible, this had negative repercussions. Due to his maturity, he exhibited understanding and forgiveness towards his parents, whilst saying that having an option to know this information would be helpful. Similarly, for Daniel, the initial reaction to not being told straightaway was one of anger, but after a time, he showed understanding and forgiveness. By saying he *"just let go",* it suggested to me as the researcher that he realised there were more important and pressing things for him to focus his attention on.

Support

A dominating theme across the literature is the need for support (Davey et al., 2011; Patterson, Pearce, et al., 2011; Wilkins & Woodgate, 2005). In the current study, all four participants mentioned aspects of support that they use or would like to have access to.

Having the Choice.

Evident in the older children's accounts was the need for having the choice of support. Jack and Rachel shared similar experiences of seeking their own support and choosing when to get it which indicated that there was still the need for independence which many adolescents experience (Silver & Silver, 2013). Jack and Rachel, aged 19 and 17, demonstrated this need for more choice by sharing how they have coped and what they would like to see more. During the interviews with Jack and Rachel, there was a noticeable disparity between how they responded, with Jack being more forthcoming and certain on what he

wanted, but Rachel appeared more reserved and uncertain. When asked by her Mum what information she would like more of to help her, she responded by saying:

"Maybe to, understand, what was going on a bit more, but I'm not sure, what difference it would have made or anything". (Rachel)

"Not really. I kind of just, deal with it myself. I don't really talk to people". (Rachel)

It seemed as though Rachel still lacked an understanding of what her Mum was experiencing as she wanted to know more about what was going on, however she displayed uncertainty in the helpfulness of this information. Although data was not collected on the stage of the parent's cancer, depending on how close it was to the time since diagnosis, it may be plausible to assume that Rachel still felt raw and was not ready for much support or information, as she was still dealing with it all herself.

When Rachel was prompted by her Mum about whether or not she would go to a support group, she replied saying *"it might take me a while, to like, want to, but if I did, then maybe, it'll probably help".* For Rachel, she may be in denial about her Mum having cancer, and by going out to get supports may make the situation more realistic and highlight the severity of her Mum's illness. By saying that it may take a while for her to want to, it signalled to me as the researcher that the type of support or how it is delivered was not important to her, but rather when she received the support.

Similarly with Jack (aged 19), he shared having gone out to support himself.

"Mostly I've gone out to support myself".

Living away from home and studying may have impacted this as he has had to become more self-reliant and take care of himself. Additionally, because he lives in a Western culture which values independence, it suggested to me as the researcher to play an important role in how he was supported. All factors together thus result in less reliance on the family and more on the self. Contrary to other findings which show that getting away from

the parent's cancer is beneficial (Patterson, Pearce, et al., 2011; Phillips & Lewis, 2015), Jack would have preferred staying at home. However, due to university, there was not much choice in his ability to move home.

"I think for some people it would definitely help not having that in your life all the time. But I think for me, it would work better if I did, in some ways". (Jack).

During his account, Jack mentioned a couple of times wanting to be back home as it would help him through his Mum's cancer and treatments which revealed to me that there was a sense of feeling stuck and therefore helpless. Due to other responsibilities pertaining to university, he did not have the freedom to move home, therefore the support he sought and received appeared to be one way to counteract this.

Jack and Rachel both showed variations in the types of support that would be beneficial to them personally and when they would like to see it, which has been shown previously in research (Patterson, Pearce, et al., 2011; Rodriguez et al., 2018). Age and gender are suggested to play a role in this, which can be seen in Jack's and Rachel's responses. Jack required more information-based support whereas Rachel wanted to know what was out there for when she was ready.

"I definitely think just being able to read information is a lot, I dunno, I personally find it's a lot easier form of support". (Jack)

"Maybe knowing what is like out there, if I wanted, anything like that". (Rachel)

External.

Having a strong relationship with family and friends was shown to be a positive support system for participants Jack and Rachel, as well as displayed by siblings Daniel and Kaitlyn. Rachel discussed talking to her friends and a peer in a similar situation as helpful to her ability to cope.

"I've just talked to friends, but nothing really like, specific or set in place […] I have one friend who lost her Mum, to cancer, so I've talked to her about it a bit".

Rachel showed that she did not have many supports in place, yet she did mention having spoken to her friends and to a peer who was in a similar position. This was the only part throughout the whole interview where Rachel mentioned the word cancer, which suggested that talking to her friends had enabled her to openly discuss her situation without fear of upsetting her Mum or family. This highlights the role that her friends may play in her life, due to the different relationship that she may have with them. Although contrary to other research (Patterson et al., 2017; Porteous et al., 2018), talking to a peer who had experienced a similar situation did not seem to affect who she was more likely to talk to.

"So even though I can talk to her about it more, I still feel the same talking to the others about it". (Rachel).

Support from external sources such as friends and peers can provide a sense of normality and reduce feelings of isolation due to being acknowledged by those around them (Davey et al., 2011; Finch & Gibson, 2009). However, children are typically more likely to turn to peers and friends if the support from family is inadequate or they are more independent due to age (Rodriguez et al., 2018). Jack's relationship with his parents appeared to be strong and was an important part of how he was coping and adjusting to his Mum's cancer.

"So I think I've a pretty good relationship with my parents, like I can tell them what's going on". (Jack, aged 19).

Although living away from home, Jack reported a good relationship with his parents, which indicated to me that he felt comfortable when disclosing what he was feeling and experiencing. However, although he indicated being quite open with his parents, there seemed to be some hesitation in talking to them. Based on his need to know more about his

Mum's cancer and treatments, I inferred that he may be more hesitant in asking questions about cancer and what his Mum was going through out of potentially not wanting to upset her.

Whilst talking to Daniel and Kaitlyn's Mum prior to talking to them, she disclosed what information they knew about their Dad's cancer. Throughout the accounts of both Daniel and Kaitlyn, they had a very good knowledge base of what their Dad was experiencing, which indicated to me that there was a strong familial bond in place, where the parents were very open with them. This in turn appeared to be helpful to Daniel as he did not display a need for professional help.

> *"Like there's some people like me that don't need professional help coz I know what's going on and I know how people can fix it". (Daniel aged 12).*

However, of interest to me, was the lack of need and desire expressed when asked about getting support from sources such as support groups. Although research highlights the importance of having support from peers in a similar situation, such as a support group (Patterson, Pearce, et al., 2011), Rachel nor Jack felt as though this was necessary for them. One reason for this was due to the busyness of life.

> *"Everybody has a busy life, and it's just like one more thing that ya have to try and make some more time for". (Jack).*

Having a Break.

Comparatively for the two younger participants, supports which gave them a break from their Dad's cancer were valuable to them. Though there was no expression of specific support they needed, both provided an insight into tools that they utilised to help them cope.

> *"It's how I, try to do things, influence my body in doing stuff […] like there's times when you need a break". (Daniel aged 12).*

"Sometimes I normally use the computer I listen to music or play games on there or I rather draw mostly because, it's just it helps me relax". (Kaitlyn aged 9).

Daniel's response indicated that playing sports where he could focus on himself and what he was doing was beneficial to him. For him to get his mind off of his Dad's cancer, focusing his mind on something specific to him appeared to be a grounding method to help him cope. Daniel struggled to articulate his points and veered off course, but of importance was being able to take a break. This appeared to include taking a break from his Dad's cancer and from school. For his sister Kaitlyn, having a break included activities which helped her relax and ones which brought her happiness. In her account, I felt as though her Dad's situation had been quite stressful and upsetting for her, which was displayed through her choice of supports that she utilised; ones which helped her to relax. Utilising such tools which can distract children with drawing and playing sports can help retain a sense of normalcy within their lives when their parent is diagnosed with cancer and can aid in retaining a sense of normalcy (Davey et al., 2011). As illustrated in the current study, being able to take a break from what was going on at home, or in Daniel's case away from school, was important for their wellbeing.

"Like I will, like there's times when you need a break, which I love to take off, days of school and stuff which helps". (Daniel, aged 12).

Accessibility and Awareness.

From the interviews with Rachel and Jack, I was made aware of a need for greater accessibility to and awareness of what is out there in terms of support and information. Rachel's Mum indicated that there had been a lack of communication from cancer organisations about the available resources and where to access them, and it seemed to be an issue even for parents who were ill.

"No, never, nobody's ever talked about websites, and actually even, really the Cancer Society haven't really, you know, given too much information, really, either. Although I haven't necessarily gone looking for it. Either." (Rachel's Mum).

"But even like, like a booklet from the Cancer Society if they know you've got children to say what, you know, you can do". (Rachel"s Mum).

Being made aware of and having access to supports and resources is one of the first steps in obtaining the help that the child needs and supporting the child to obtain these is crucial (Kennedy & Lloyd-Williams, 2009; Patterson, Pearce, et al., 2011). For children, the way the information and support is delivered is an important point to consider. As I discovered during Jack's account, if information is not delivered in an age-appropriate way, awareness of such resources and accessing them can be hindered. Jack suggested one option, especially for adolescents, which was the utilisation of social media.

"I think accessing the information, like, Facebook or the internet would be a lot easier than brochures I think. Even websites might not be, as accessible as something on Facebook, or anything like that". (Jack).

Elaborating upon this, Jack shared that having to go to support groups was harder than having support and resources easy to hand. Maintaining a balance between school, work, and personal life in addition to extra commitments can become too overwhelming and difficult to manage.

"ya' know, everybody has a busy life, and it's just like one more thing that ya' have to try and make some more time for. Whereas if you can just read information you can do that whenever". (Jack).

From this excerpt, it indicates that resources need to be easy to access and obtain.

Living in a culture which prioritises having a busy schedule and having everything easy to access due to smartphones, creating online supports is shown to be a helpful

component in coping with a parent's cancer diagnosis. Similarly, Rachel and her Mum disclosed not having been made aware of what is available, nor being provided with much information. However, Rachel had not thought much about wanting to receive anything.

> *"Kind of. I didn't really think about, No. Like I haven't really received anything, but I didn't think about, like wanting, to, really. But I guess if I would have, then it might have helped or something". (Rachel aged 17).*
>
> *"You haven't received a great deal of information, have you?" (Rachel's Mum).*

Though they had not gone looking for resources, signposting by organisations, especially when working closely alongside these families, may combat this lack of awareness and access. It appeared to me that there had not been enough done for this family through public groups, but there was support offered through the private institute that Rachel's Mum went through for treatment.

> *"[talking to Rachel] you can go and see the people. Coz I've gone privately for all my chemotherapy and stuff, so. There's a psychologist". (Rachel's Mum).*

Near the end of Rachel's account, when I asked if there was anything else that she wanted me to know or any information that she would want healthcare professionals to know, she reiterated the point of wanting to know what is available for when she is ready.

> *"Just as Mum said, maybe knowing what is like out there if I wanted, anything like that". (Rachel).*

Emotional.

Having a parent diagnosed with cancer is an emotionally tough time for all family members. Stress, uncertainty, and the changes involved in the diagnosis of a parent or family member makes for a tumultuous time. The emotional impact was highlighted strongly across all interviews through body language, answers, and tone. For Rachel, she displayed a sense of

discomfort when discussing her experience, disclosing that opening up about feelings was harder than asking questions.

"Like talking about how I feel and stuff, is worse than, like harder, than just asking questions." (Rachel).

This excerpt emphasised the struggle that she was having discussing this information and her struggle when it came to disclosing how she felt. Due to my position as a researcher, my aim was to listen and not prompt her further. Just from her interview she displayed a high level of discomfort when it came to sharing her experiences. This indicated the impact that this situation had on her and how much she was struggling with the severity of her Mum's illness, especially with being vulnerable in front of her Mum.

Every child deals with adverse circumstances differently, and some do not want to share how they feel out of worry that it could further upset the parents, make them feel worse, or just not knowing how to (Kennedy & Lloyd-Williams, 2008). Feeling supported and comfortable in opening up is crucial in alleviating any fears and preventing the child from bottling up how they feel, and for Jack, his ability to discuss openly what was going on for him was supported through having a good relationship with his parents.

"So I think I've quite a good relationship with my parents, like I can tell them what's going on." (Jack).

This reflects the findings from the 2017 meta-analysis by Ellis et al., whereby the authors found three factors important to the development of future interventions. One main one was providing children with a comfortable environment where they can openly talk through what they are feeling. Emotional support does not have to just come from the home environment but can also come from within the school. As Daniel (aged 12) shared, his school offered professional support as a way to discuss anything going on at home, which in turn would have helped him to process any feelings he was experiencing.

"Like with my school like, I do counselling and stuff […] so I'm fine to talk to someone who wants to help me". (Daniel aged 12).

"So I'm fine to talk to someone that wants to help me, it's just I'm not happy to talk to someone then they harass me […] if someone's going out of their way to come and say help me or influence me to feel good or something like, to do a study like you are doing now, so I'm fine with that". (Daniel).

Having genuine support was shown to be valuable to him by providing him the space to talk. Emotions can be heightened during such a tough situation, and without the space, time, and support to discuss what they are feeling, children are more susceptible to displaying feelings such as sadness, worry, anxiety, and even depression (Silver & Silver, 2013).

Time

The concept underlined some of the needs that children had when it came to their parent's cancer. This included a need for understanding the timeframe for the illness, what the future would look like, and an increased desire to spend time with family.

Time with the Sick Parent.

Three participants in the current study all indicated a need to have more time with their sick parent. This was especially so for the younger two, who, although their Dad having cancer was really hard on them, they saw that having more time with their Dad was a good aspect.

"There's like a good side to it and a bad side to it […] But like the good thing is that I get more time with him, coz he doesn't coach tennis as much, he still does, surprisingly". (Daniel aged 12).

Daniel expresses the importance of having time with his Dad and it begs the question of how much time he got with his Dad prior to him becoming ill. The need for time with his Dad is suggestive of the close relationship between them, which could be in part due to

Daniel's gender (McDonald et al., 2016; Thastum et al., 2009). It also highlights the importance of the role that his Dad had in his development as he is still quite young and dependent on his parents. Younger children who are still reliant upon their parents may have a greater need for time with the sick parent, as the parent still has an influence over them. The parents are the main source of information for many children and this is displayed in Daniel's account. Time spent with his Dad had helped him to be more aware and understanding of what his Dad was experiencing.

Parents with cancer tend to have less energy and spend more time at home. For younger children, this means that they get more time with them. Although young children may not fully grasp the severity of what is going on, having their parent's attention is important for growth and development. Kaitlyn's account of her experience emphasised the significance of getting her Dad back home with her and her family, regardless of how much his treatment cost.

> *"So we were so relieved and the drug is quite expensive but we were up to it and we wanted Daddy home safely and with us". (Kaitlyn aged 9).*

Kaitlyn's use of *"relieved"* reflects the anxiety and distress that she and her family were experiencing when her Dad was diagnosed. With the introduction and match of the drug to her Dad, it signalled to her that her Dad would be able to come home. Having been separated from their Dad for approximately seven weeks, siblings Daniel and Kaitlyn expressed the need to spend more time with their Dad and the positive effect it had on them during this experience. This suggests that they were more appreciative of the additional time they got with him after being separated for so long.

Jack (aged 19) discussed the toll that his Mum's cancer had on him, stating that he wanted to be back home, as the changes in his Mum would be more gradual rather than as shocking as they were for him at the time.

"Yeah, I think so. I think ultimately coz I, yeah it was pretty shocking just coming back at one point and seeing my Mum and she'd like, just was really struggling to walk and something". (Jack aged 19).

"As opposed to being there all the time, it's more of a gradual thing that you can slowly get used to I guess".

During Jack's account, he mentions multiple times the importance of being home and how much that would help. The separation from his family seems to cause a lot of stress and concern for Jack as he is not able to see what is going on with his Mum and is thus problematic when it comes to him understanding what his Mum is experiencing. For these three participants, the stress of family separation appears to create a lot of strain on them and hinders their knowledge of what is going on. The more time they get with their ill parent, the less shocking any changes can be as they are able to see themselves what is occurring in the course of the cancer and treatments.

Helping Out.

Given the value placed upon spending time with the sick parent mentioned above, many children find ways of helping out so that they can be more involved in the sick parent's life. Two participants in the current study discussed how they helped out with their parents, whether they were at home or not. Implicit in Daniel's account is a greater sense of urgency when it comes to completing tasks within the house.

"He used to ask me to do stuff I'd like get off my chair and then 20 minutes later do it. But now like I'll get on and do this for him". (Daniel aged 12).

And later…

"[I] sometimes make my Mum and Dad tea and that's a plus". (Daniel aged 12).

This is suggestive of a greater willingness to do tasks around the house when asked of him, highlighting just how aware children can be when a parent has a serious illness. Not

only the way that tasks were done in the house had changed, but also the time in which they were done. Whilst listening to Daniel recount his experience to me, he exhibited a high level of maturity and awareness of what was going on around him and the added responsibilities. Through actively helping around the house, children may feel like active contributors to the family and more involved in the parent's illness, in addition to a sense of normality being sustained (Maynard et al., 2013). Due to less expectations and responsibilities placed upon younger children, tasks such as making a cup of tea for parents and letting the sick parent sleep more may not be a big change to older children, but for children Daniel's age and younger, these tasks can have a noticeable impact on their daily lives.

Children typically assist more in jobs around the house when a parent or other family member is ill so that additional home-based stress can be alleviated (Phillips, 2015). Yet this is not the case for all children. Some may display a sense of helplessness if there is no apparent way for them to help due to living away from home. Jack shared how he helped his Mum in an innovative way, by researching other means of treating his Mum's cancer.

> *"I read through a couple of theses for my Mum to understand some different approaches with treating cancer […] and so I read a couple of theses for her to explain that" (Jack).*

Jack explained that the purpose for reading these were for him to explain to his Mum different treatments. Implicit in this account is the need to help out more and find a new avenue for treating his Mum. Even though he tries to be realistic about the situation, I felt as though he was trying to maintain a sense of hope by finding a potential new treatment which would help his Mum.

The Process.

Knowing what to expect and what goes on during the course of the parent's cancer and treatment is valuable knowledge for children. Jack expressed an interest in knowing more about what each stage of treatment was going to be like for his Mum.

> *"I think it would be good, I guess to just understand, like wh-, like a time frame for what the process would be". (Jack aged 19).*
>
> *"I don't really understand maybe what the process is to what is happening with my Mum". (Jack aged 19).*

This alludes to Jack's lack of knowledge on more basic components to his Mum's cancer, as he did not know what each component looked like. The apparent need for information was reiterated twice by Jack, suggesting that it may assist in preparing him for what might come next. Having an approximate time frame of what each stage looks like and what it might mean for him and his family in terms of what they can do and how to prepare is valuable to Jack. Although Jack struggled to verbalise what he would want and what would be beneficial for him, his repetition of requiring this knowledge asserts the value in preparing children for what may come.

The Future.

Having a parent diagnosed with cancer is a time of uncertainty, as sometimes there is little knowledge of what the future looks like. Jack's apparent lack of information of what the process may be like and what this situation holds for him is a topic which holds his attention. He describes knowing more about what it means for him and his parents as reassuring for him.

> *"It would be a bit more reassuring to know, I guess like what, what does this mean for me, like what does this look like that's going to be happening to my parents, over the next 18 months or so". (Jack aged 19).*

In this excerpt, Jack mentioned a specific time frame of approximately 18 months, which may be due to the severity and stage of his Mum's cancer; stage 4. He indicates an awareness of the severity of his Mum's cancer by doing so, which alludes to feelings of depression and a lack of comfort. It is common for timeframes and prognoses to be topics that children have questions about (Silver & Silver, 2013), as they need to know what may happen to their sick parent and in turn themselves.

> *"Like after so many months this is going to be happening, and then we're gonna look at either doing this or this". (Jack).*

The use of *"we're"* implies a collective impact of cancer on the whole family and the long-lasting ripple effect that losing a family member to cancer can have. Discussing potential outcomes and the longer-term impact on him and his parents seemed to be comforting, and by offering children this information it may relieve children of worries and misconceptions about what the future may hold.

Communication and Information

The key to minimising the impact of a parent's cancer on children is communication (Finch & Gibson, 2009). Throughout the literature and in the current study, communication and information are discussed as essential in helping them cope. Yet, it is shown to be a need which typically goes unmet (Ellis et al., 2017).

With School.

Communicating across all environments, especially with schools is crucial in supporting children. If schools lack information on what is going on for the child at home, feelings of stress, anger, confusion, and feeling unsupported are shown to increase (Chowns, 2013). Daniel shared the conflict he faced and what school was like for him.

> *"Like the stuff at school which sometimes helps and sometimes really like, annoys me". (Daniel, aged 12).*

As prior research has shown, school can be a place to escape to through providing a sense of normality to daily life, yet at other times it can add stress to the child due to homework and teachers (Chowns, 2013). The disparity in Daniel's view of school indicates that his feelings about school are situation dependent. During this excerpt, it suggested to me that depending on what was happening at home with his Dad, school was annoying, which was why he would ask his Mum to take days off. Having to focus on other tasks at school whilst the child's parent is ill can lead to being distracted and stressed. Daniel went on to further share with me the value in taking days off.

> *"Like there's times when you need a break, which I love to take off, days of school and stuff which helps". (Daniel, aged 12).*

Supporting work by Chowns (2013), Daniel displayed a sense of contention between liking school and disliking it, finding it both a place of consistency and a place of stress. His response highlights how hard it can be for school-aged children who face the stress of having a parent diagnosed with cancer and their responsibilities at school. Notwithstanding, it is important to remember as the researcher though, that this may also be due to his age, as young children do not always like going to school, regardless of what is going on at home. Thus, in order to determine what is causing the child to be stressed at school, communication between parents and teaching personnel is vital which in turn can lead to the offering of support such as counselling. When asked what he would find helpful, Daniel revealed that he saw a counsellor at school. The combination of asking what he would find helpful and his disclosure of seeing a school counsellor appears to suggest that this is a useful avenue of support for him.

"Like with my school, like I do counselling stuff". (Daniel aged 12).

This suggests that his parents have been open with the school about what has been going on so that Daniel and his sister are adequately supported at school.

At the Start.

When inquiring about the type and amount of information that children would like to know more about, Daniel and Jack both desired information from the start as both were aware that their parents had tried to keep information from them initially. It appeared that for Daniel, this required a level of understanding as to why his parents did so, thus indicating the potential for conflict between how he felt and how he felt he should feel (i.e. more understanding).

"Like it took my parents about a month to tell me what actually was going on". (Daniel, aged 12).

"I'm not happy, I'm not angry […] but like at the start when I didn't get told, yeah. But I just let go". (Daniel).

Lack of communication at the start can elevate feelings of anger, distress, and anxiety (Davey et al., 2011; Ghofrani et al., 2019), especially if children find out through other means such as at the hospital (Huang et al., 2014). Not being told straightaway had evidently led to feelings of sadness, anger, and even hopelessness. Yet, he eventually he let go, which may have been his way of supporting his parents so as not to make them feel bad for the lack of information at the start. This was also for his own wellbeing, as he described already feeling hopeless because of his Dad's illness. He explained how he felt as a point between being angry and sad at the same, which was likened to depression. This accentuates the disparity in feelings and this captures the range and severity of emotions that children can experience, especially when they feel excluded.

"But when you're like going through a point where you're, hopeless. Like a point where you feel angry and sad at the same time. Like depression". (Daniel, aged 12).

Similarly, Jack sensed that his parents had chosen not to tell him everything right away. Though children may not fully understand why, research highlights a couple of reasons

why parents may do this, including worrying about breaking down in front of the child, a lack of awareness of the child's distress, and fear of upsetting their child (Kennedy & Lloyd-Williams, 2009).

> *"I got the impression that my parents had tried to maybe not tell me everything that's happening right at the moment just to not overwhelm me or anything, which is fair enough as well. But I think it would be nice to have the option to find out that kinda stuff". (Jack).*

In Jack's situation, he shows an understanding of why his parents may not have told him much straight away, yet it was bothersome for him. Wanting the option to know more about the cancer and the parent's prognosis is an indication of readiness for knowing more. I got the impression that Jack had struggled initially with not being told, and through tone and body language, it was something that appeared to still be bothering him. Like Daniel, Jack displayed a sense of reasoning through saying *"which is fair enough"*. Although he wanted more information and communication from his parents, he understood that it may have been in his best interests to not know everything.

Open.

Findings on openness of communication were mixed amongst three of the participants. Rachel shared that open communication and ease of talking occurred only sometimes within her family, yet this may have been due to Rachel's struggle with discussing how she felt and her ability to be open with her family, whereas for Daniel and Jack, communication was less of a struggle.

> *"She's always been quite a hard nut to, crack. But emotionally, like she'll just sorta keep things, and it does sorta take a bit to get her out". (Rachel's Mum).*

Having Rachel's Mum present during the interview had provided a deeper insight into Rachel's experience and how she had coped from the perspective of a parent. The

comparison between Rachel and being *"a hard nut to crack"* implies one of two things for Rachel: firstly, for her to open up it was important to persist; secondly, and most probable, it was important to make her aware that she can ask questions and talk when she wanted to, but that she needed time and space to do so. This stresses the importance of making sure that communication is open between both sides; having the parents create a space for the child to talk and for the child to feel comfortable in doing so. (Silver and Silver, 2013, p. 35). Jack's experience differed to Rachels, as he reported having an open relationship with his parents which made it easier to discuss with them what was going on.

"I've been, quite open with my parents for a lot what's going on". (Jack, aged 19)

"So I think I've quite a good relationship with my parents. Like, I can tell them what's going on". (Jack).

Although Jack specified information as his preference for support, these excerpts imply that his family was a support which he utilised. Through open discussion with them, he was made aware of what was going on and may even have felt comfortable in discussing what he was feeling. The combination of a lack of interest in a support group and the openness with his parents was suggestive of less of a need for additional support. This indicates that for some children, when communication is open between their parents and them, there may already be a substantial amount of support in place. Though Jack mentioned only being *"quite"* open with his parents for *"a lot of what's going on".* This suggests that some aspects of what was going on he may have been more hesitant to discuss, such as emotions, whereas for others he was not (e.g. questions, what he has been doing). Therefore, this illustrates the vastness of what communication comprises of.

Parents are one of the main and most readily available sources of information for children and they are highly valued (Huang et al., 2014). This is unlike previous research which suggests that it is older children who require open communication (Morris et al.,

2016), results in the current research indicate otherwise. One of the youngest participants, Daniel, displayed mixed feelings about whether he would like to know more about his Dad's cancer.

"At times like you want to know more, and at the same time like you don't". (Daniel).

Young children are also susceptible to concerns and worries about their parent, requiring open communication about what is going on. Open communication is not just about keeping the child informed, but it also extends to what they would like to know more about and if they want to know more. Daniel shared that he had been asked a *"tonne"* about whether he would like to know more or less, which appeared to be something which he struggled with, as was articulated in the above excerpt. By keeping the communication lines open between parent and child, it can create an environment where both can approach one another to discuss the illness, as "communication is a two-way street" (Silver & Silver, 2013, p. 35).

Having the Conversation.

While three participants discussed the importance of having the conversation about the parent's cancer, there were variations in what this meant and how it was conveyed. Jack acknowledged the importance in discussing what his Mum was experiencing, sharing that his parents updated him on appointments and the stage that his Mum was at in terms of treatment.

"One thing when I'm around, they'll explain, ya' know what's happening if they're going to a certain appointment and stuff".

However, this suggests there may have been a lack of discussion when he was not at home. Jack said that when he was around they will explain certain appointments and other aspects, which is suggestive of this occurring only when he was at home. This might even indicate some hesitancy on the parent's part, as *"certain appointments"* may refer to more

serious or important appointments, whereas routine check-ups they might not have disclosed, or vice versa. It is plausible to assume that children who live away from home or who are younger may be at a greater risk of being less informed than those who are older or live at home. As a result, it is paramount that parents have the conversation about what stage they are at and inform the child as much as they can and for however much the child needs.

When a child is not aware of what is happening with their parent's cancer, it may lead to them searching for information themselves. As can be seen in Jack's account, where he expressed a desire to know the information about his Mum's cancer and what she was experiencing.

> *"It would be nice to have the option that if I wanted to find out that kinda stuff I could".*

This captures the importance of discussing the illness with children and giving them the time and space to do so. Because Jack's parents had not been forthcoming about his Mum's cancer, even though it may have been to protect him, his need for better communication was high. However, not all children want to discuss their parent's cancer and what is going on. Rachel on the other hand, displayed difficulties when talking and asking certain questions, in addition to answering questions.

"I don't really talk about it". (Rachel aged 17).

Her Mum's cancer seemed to have impacted her greatly, with emotional aspects being harder to discuss. However, she was not one to talk to other people, which was evident through her body language throughout the interview and her Mum sharing that she was not one to talk much. So for her, having the conversation did not appear to be helpful.

> *"But you've never really been one for talking to other people really". (Rachel's Mum).*

"Maybe, to understand, what was going on a bit more, but, I'm not sure, like what difference it would have made or anything". (Rachel aged 17).

Rachel appeared to lack knowledge on what was happening and even hinted at wanting to know more. Yet based on her previous comments about not wanting to know more and seemingly struggling with her Mum's cancer, she felt as though better knowledge would not have helped her. Rachel was very hesitant in disclosing what the experience had been like for her and was uncertain of what it was that she needed or wanted in regard to information and communication.

The contrast between each participant's account and preferences highlights the importance in gathering enough information from them. This is so that parents and professionals are made aware of the struggles that children may face, in addition to the amount of information and support that they may require.

"At times like you want to know more and at the same time you don't". (Daniel, 12).

The Positive.

When hearing of a cancer diagnosis and having little background knowledge, worse-case scenarios can be a common response. Many may turn to the internet which typically provides them with fear-inducing facts which may not be true for that person's situation. For one participant, this was evident as they had gone out searching for information which aided them in knowing more about the detailed aspects of cancer such as the metabolism and ways in which to attack it.

"I read through a couple of theses for my Mum to understand some different approaches with treating cancer, based on my uh, attacking the metabolism of the cancer […] other than that I haven't looked into too much else". (Jack, aged 19).

It is apparent in this excerpt that Jack was more interested in potential and viable treatments for his Mum, with him predominantly looking into this area. Due to the severity of

his Mum's cancer, his searching for treatments may indicate that there is a greater need for more positive information which can instil a sense of hope into a tough situation. Therefore alleviating fears pertaining to the cancer and decreasing time spent searching online, due to an increased understanding (Silver & Silver, 2013).

Likewise, the youngest participant Kaitlyn (aged 9), shared that she wanted to know more good information than bad.

"I would probably want to know about the good things about my Dad and his cancer, or the bad things I don't really want". (Kaitlyn aged 9).

The impact of knowing about the severity of her Dad's cancer at such a young age was difficult. Throughout the interview, she displayed a high awareness about her Dad's cancer and the seriousness of it. Thus, knowing more about the positives may provide some reprieve from all of the negative feelings that she has experienced. Kaitlyn mentioned twice about the desire to know more about her Dad's choice of treatment, suggesting that it is quite a new drug treatment. Specifically, the rarity of the match rate (a 1% chance success) which her Dad had achieved was a big positive for her and her brother. Thus, understanding the benefits of their parent's treatment was proven to be valuable in being more realistic and reducing worries and fears.

"Probably finding, like, probably getting like other types of ways to, add money wise, or […] It's a lot of money the drug, so probably some sort of key to, finding out what this drug is really able to do". (Kaitlyn aged 9).

"Yes [I like to know a lot], I like to be like, completely realistic about the situation". (Jack, aged 19).

Jack's approach in reading through theses for his Mum on different cancer treatments indicated a substantial need for better communication from his parents on what his Mum's treatment was and how it worked, so that he could understand the benefits. Children who

witness the positive changes their parent experiences may instil some joy and a new sense of hope within them. For siblings Daniel and Kaitlyn, they displayed shock and excitement at their Dad's increased ability to do everyday tasks such as walking the dog.

> *"later he was like, wanting to walk the dog around, he was like, wanting to help everybody, and I was like woah". (Daniel, aged 12).*
>
> *"he was actually was feeling way better. He could walk the dog, he's gotten a few tennis lessons in still." (Kaitlyn, aged 9).*

Awareness of Others

Throughout all four transcripts, each child showed to have different ways of coping, different understandings, variations in needs, and a good sense of others. For some children, they appeared to have a greater sense of empathy for others. And as found previously, children often develop an increased level of empathy and awareness of others (Kennedy & Lloyd-Williams, 2009; Silver & Silver, 2013), as they know what it's like to experience such an event. As shown in two interviews, participants indicated an awareness of other children going through a similar situation. When Daniel was asked about what he would find helpful in terms of support and/or information, because of how he had felt, he knew what others may feel when experiencing something similar.

> *"I'll say like, things for other people's needs like, or they'll probably want more of a choice like of what they wanna do. Like there's some people like me that like, don't need like professional like help, coz I know what's going on and I know how people can fix it […] there's like people out there that just feel sad because they can't see their parents. Like I felt like that when my Dad was having like […] when he had pneumonia and that lasted for two weeks". (Daniel aged 12).*

Rather than just answering what he would like to see, it was evident that Daniel placed himself in the shoes of others in a similar situation so to speak. I observed a high level

of awareness from Daniel throughout his interview, and that through his situation, he was able to utilise how he felt and what he knew to see how others in a similar situation might feel. Through utilising such information, there is a more genuine and deeper insight into the experiences and needs of children, and they understand what it is like to experience having a parent living with cancer. Likewise, Jack displayed a similar awareness of what others may need who are experiencing a similar situation.

> *"I think, for some people it definitely help not having to have that in your life all the time, but I think for me, it would work better if I did. In some ways". (Jack aged 19).*

Jack displays a great awareness of what other children may need and would prefer, suggesting that he is cognizant that everyone is different and requires different support and resources. As a result of his own situation, Jack indicated to me that he was able to put himself in the shoes of others and was able to voice what they may need. And as research shows, empathy and awareness of others is shown to increase amongst these children due to a greater understanding of what it is like to experience such adverse circumstances (Kennedy & Lloyd-Williams, 2009; Silver & Silver, 2013).

Family Separation

Being in Aotearoa/New Zealand, cancer treatment centres are located in the bigger cities which means that when a family member is diagnosed with cancer, they may have to travel some distance if they live in smaller community or rural settings. For the two youngest participants, this was something that they experienced for seven weeks when their Dad was hospitalised in a different city.

> *"Then he went to Christchurch with us and then we felt like it was a little upsetting for us […] So then he had the tests and we felt really sad. We had to leave him in hospital for 7 weeks". (Kaitlyn aged 9).*

Families who are separated due to treatments and other hospital visits can experience far greater disruptions and troubles than families who do not have to travel far. Kaitlyn's response to what the experience of having a parent diagnosed with cancer had been like for her showed the immensity of the situation and the impact that it had on her and her family. Still being such a young age means that she was still heavily reliant upon her family and displayed this in her use of *"we"* and *"us"*. As the researcher, I interpreted this as her viewing the family as one collective unit, which was broken up for seven weeks. Kaitlyn's initial response was sadness, due to the distressing nature of being separated from her Dad. However, there was some hope due to her Dad being placed on a drug which allowed him to come home.

> *"But then something happened and when, Daddy, he got, his test done, there was this drug that could actually help him in his life basically […] so we were so relieved and the drug is quite expensive but we were up to it and we wanted Daddy home safely and with us". (Kaitlyn, aged 9).*

Having to be separated from the sick parent can be traumatic for children and an added stressor to what their parent is already experiencing. Kaitlyn displayed the stress that the family was under due to the cancer, which emphasised the toll that would have on the family when they were separated. For her, having her Dad home with her was crucial, as was pointed out through her saying that they were up to paying for the drug regardless of its cost. This emphasises the troubles and trials that families may have to face, in addition to the differences in what may be involved in cancer treatment, depending on where the family is located. As was illustrated by Daniel, there is a greater need of support which may have benefited him during this time.

"There's like people out there that just feel sad because they can't see their parents. Like I felt like that when my Dad was having like […] when he was in hospital for like months". (Daniel aged 12).

Although Daniel felt as though there was not a need for support for himself, I felt as though through this excerpt, he needed some form of support around the time of his Dad being away in a different city. The emotional impact that this situation had on him was tough and not having his Dad there like he normally, was strange to him. It is probable to assume that family separation can elevate feelings of worry and stress as they cannot see what is going on with the sick parent.

"Like there's some people like me that like don't need professional help coz I know what's going on and I know how people can fix it". (Daniel).

Similarly for Jack, living away from home for university and not always being around during his Mum's cancer had affected him substantially. It was one of the most challenging aspects for him as he was not always sure of what was going on and was shocked whenever he saw a change in her.

"Especially being down here in Christchurch, and they're in Wellington, of course, like I don't really see what's going on a lot of the time". (Jack aged 19).

"One of the challenge-, most challenging things is actually, like being down here for of course most of the year and for the small holidays that I may go back for, there may be like big changes in my Mum's health between that point and then. So it can be quite, I dunno, overwhelming to have to see that. As opposed to being there all the time, it's more of a gradual thing that you can slowly get used to I guess".

I noticed that Jack's lack of opportunity to see first-hand what his Mum was going through was an issue of concern for him, as it was something that he kept having to get used to each time he went back home. The shock of any change appeared to be greater than it may

be for others who live with their family. I felt as though for Jack, his Mum's cancer and the reality of it was just as raw each time he went home as it was the first time, as he had to readjust to his Mum's new state and then shortly after have to go back to university. So, not only do children have the initial reactions to a parent's diagnosis, but there can also be continuous reactions to any changes, especially when they are separated.

Conclusion

The main themes were strongly pointed out by all participants, but the subthemes were better articulated by one or two participants, as they were specific to their situation. As per Smith and Osborn (2004), each transcript was looked at individually due to the small number of participants. Analysis was not seen in the traditional qualitative sense whereby the researcher looks at each transcript individually, re-reading a couple of times and finding converging and diverging themes across each one.

Within the current study, results revealed a number of different themes and subthemes from the participants, with many needs being highlighted. There was an even spread of ages (ages nine, twelve, seventeen, and nineteen) and of gender (two girls, two boys) which gave a more representative look into the experiences of children of cancer patients. Of interest to me as the researcher was the difference in the amount of information shared by participants based on gender. Both males shared substantially more information than the girls did, with analysis going deeper for their two transcripts. Factors such as willingness to talk, comfort, age, and presence of others may have impacted this.

However, due to my background in psychology and my role as the researcher, I was mindful to not push for further information. I was aware of their ages and situations and respectful of not pushing for further information as my role was to listen and prompt only when clarification was needed. All participants indicated that having a parent with cancer was hard on them and the changes that they experienced had affected their day to day lives.

Although one-on-one or group support was not mentioned as something of value to the participants, each shared different ways that they had gone out to support themselves in the less traditional sense. This included drawing, researching about their parent's cancer, playing sports, and talking to friends occasionally.

Additionally, time was a crucial factor which came across in multiple participant's transcripts. Due to the uncertainty of their parent's situation, many found comfort in spending more time with the ill parent, helping more around the house, and knowing more about the process and future. Unlike the theme of support, information and communication were discussed by the three oldest participants as something they would like more of, especially at the start when their parent was diagnosed. Having open communication with family and school were shown to be important factors in supporting the child and allowing them to approach parents to ask questions. For two participants, Jack and Daniel, their awareness of others was prominent in their responses to what they would like to see in regard to support and information. Rather than answering what they would prefer, they suggested what other children may find helpful, thus displaying a great sense of empathy and understanding of others. The last theme reflected the issues faced by children when they were separated from their family, whether due to hospital and treatment visits or living away from home for university. It emphasised the importance of being near to the family and being involved in what the sick parent was going through.

Overall, the themes which emerged from the analysis phase all highlight the struggles that many children can face when their parent is diagnosed with cancer and the support and information that they require. The following chapter will summarise in detail each theme alongside previous literature and what the current results mean for future research and practice.

Chapter 6 – Discussion

Walking a mile in someone else's shoes isn't as much about the walk or the shoes; it's to be able to think like they think, feel what they feel, and understand why they are who they are and where they are. Every step is about empathy.

Toni Sorenson.

This research aimed to explore the experiences of children who had a sibling or parent diagnosed with cancer and what their information and support needs were. This was achieved through the use of semi-structured interviews with four children and one parent. Due to organisational issues faced during the recruitment phase, this study only looked at the experiences and needs of children of cancer patients, not siblings.

Six themes and seventeen subthemes developed during the reading of transcripts; change, support, time, communication and information, awareness of others, and family separation. Using IPA as the methodology ensured that the themes which emerged from the transcripts were reliable and valid across participants. Although not every participant discussed each subtheme, the overall themes were discussed by all participants.

Due to my role as the researcher and my experience in psychology, I was aware of the sensitive nature of the topic and the questions which were asked to a group of children varying in age. I was mindful of not pushing for further information as the role of the researcher is to listen. Therefore, throughout the transcripts the information was provided freely with little prompting from me; only when clarification was needed.

This chapter will summarise the themes as they relate to prior research. Limitations of the current study, recommendations for future research, and the implications that these findings have for future research are discussed.

Summary of Findings Related to Existing Research

Theme one: Change.

The theme change encompasses all that children can face during a parent's cancer. All four participants in the current study discussed a new normal which they had to adapt to at home. For one participant, Daniel, he referred to it as a change in the cycle of how tasks were done at home and the way his family functioned. This included helping more around the house and increased responsibilities. Although this may appear to be bad for some as it means less socialising with friends, Daniel saw it as a positive. *"[I] sometimes make my Mum and Dad tea and that's a plus".* For many older children, these types of responsibilities can be seen as a burden, yet for Daniel they were taken as a positive. Which suggests that there may be age-related differences in how this change is perceived, which future research would benefit from unpacking. Due to more effective treatments available to their parents, two commented on their Dad's ability to do things again that he was able to do pre-illness. This gave him *"a second chance at life" (Kaitlyn, aged 9),* which indicated a sense of normality restored. Although there was negative change regarding their parent's illness, these results show positives which can help them cope.

Change was also discussed regarding the physical change the child's parent experience and the impact it had on that child. Jack shared that it was one of the most challenging aspects of his Mum's cancer, which was evident in how he was struggling to articulate this experience. As research shows, when children are separated from the ill parent, any change that the parent goes through can be heightened (Garrard et al., 2017; Rodriguez et al., 2018), and as a result, can lead to feelings of shock and sadness. In addition to challenging their ability to cope as was articulated by Jack. Without appropriate support and preparation, these children can face greater adjustment issues and poorer psychosocial outcomes. For two participants, Jack and Daniel, depression was mentioned as something they had experienced. For Jack, he shared that he developed depression due to the

accumulation of both prior negative events and his Mum being diagnosed with cancer. It was something that he still struggled with and was getting continuous support for and illustrates the impact that parental cancer can have on children. These findings support prior research which suggests that children of cancer patients are at a higher risk of psychosocial problems such as depression and anxiety, especially amongst adolescents (Compas et al., 1994; Morris et al., 2018; Sieh et al., 2013). However, an important finding in the current research suggests that younger children may also be susceptible to experiencing or developing depression. This was shown in Daniel's (aged 12) transcript, where he likened his feelings of anger, sadness, and hopelessness to that of depression. Using this knowledge, healthcare professionals are better equipped to screen children at risk of developing poor psychosocial outcomes and therefore provide these children with the necessary support.

Theme two: Support.

Support was a prominent theme which all four participants discussed. The need for support is also a common theme across the literature which reveals that children all display different levels of need and types of support that they require such as variations in depth of information required and whether they require face-to-face support (Davey et al., 2011; Patterson, Pearce, et al., 2011; Wilkins & Woodgate, 2005). The two older participants within this research highlight the importance and value of having the choice in the type of support offered. Both Jack and Rachel shared their desire of seeking out their own supports and resources so that they could receive help when they needed. Due to being adolescents, who tend to distance themselves from family as a result of a greater need for independence (Morris et al., 2018; Patterson et al., 2017; Silver & Silver, 2013), Jack's and Rachel's responses highlight the value in offering supports and resources which they can access in their own time. Although previous research highlights the various types of support children

require, results have not shown a need for the choice of support (Kennedy & Lloyd-Williams, 2009; Rodriguez et al., 2018).

When it came to outsourcing support, external support appeared to be important for most participants, whether it was from family, friends, or peers. Rachel, who did not always find that she was comfortable asking questions and talking to her family, talked to her friends and one peer who was in a similar situation when she needed to. Jack though highlighted the benefits of having a close, strong relationship with family, as it assisted him in opening up to his parents and telling them what was going on. Although Rachel's response supports prior research of turning more to friends and peers when children get older (Maynard et al., 2013; Patterson, Pearce, et al., 2011), Jack shows the opposite. The variations between the two is indicative of how children cope differently and the need for organisations and healthcare professionals to offer different ways to receive support.

Contrary to other research which demonstrates a need for support groups (Alderfer & Hodges, 2010; Davey et al., 2011; Wilkins & Woodgate, 2005), children in this study did not display interest in or a need for them. This may be due to having a close familial bond whereby they have the support they need already, or even due to the 'she'll be right' mentality within the New Zealand context. Support groups, especially closer to the time of diagnosis, are beneficial in normalising feelings and improving mood and behaviour across all areas (Davey et al., 2011). Yet for some children, such as those within this research, this does not appear to be valuable. When looking at this from a New Zealand perspective, New Zealanders are known to not go out to receive support due to stigma, lack of awareness, or lack of accessibility. Future research within this specific context would be beneficial.

The two youngest participants, Daniel and Kaitlyn, discussed a different type of support. For them, this was having a break away from their Dad's cancer and other stressors (e.g. school). When reflecting upon what tools aided their ability to cope, they shared having

time off school, listening to music, keeping busy doing physical activities, and playing games on the computer. Kaitlyn's (aged 9) preference was drawing as it helped her relax, which is shown in the study by Phillips (2015) whereby children tend to utilise tools which enable them to take their minds off of their parent's cancer. Furthermore, as Daniel and previous results show, having a break from school can be beneficial as it sometimes can be a place of additional stress (Alderfer & Hodges, 2010). Daniel reported that there was a good and bad side to school, whereby sometimes it enabled him to have a break, and other times it was a place to escape from.

Older participants mentioned a need for more awareness of, and accessibility to resources available that they could utilise. Rachel's and Jack's age (17 and 19 years respectively), social media was mentioned as a source which would be most beneficial in providing them with information and support if the need arose. This is due to greater accessibility of this platform for this age group. Yet, when speaking with Rachel's Mum, there was discussion about a lack of communication from organisations about available resources. It is important that when working alongside these families, they are made aware of resources available and from reputable sources (i.e. cancer organisations), given the array of online sources that are not always evidence-based or updated. Similarly, in line with previous research (Kennedy & Lloyd-Williams, 2008), one of the main barriers to accessing resources and support is that it is not presented in an age-appropriate way. If resources are not delivered in a developmentally appropriate way, then they are less likely to access it, as was highlighted during the interview with Jack (aged 19).

The emotional impact of having a parent diagnosed with cancer was articulated by all participants. As the researcher, I observed the discomfort and sadness from the participants in their accounts of their experiences, thus, emphasising the need for greater emotional support. However, it also seems to be one of the least adequately met needs for children of cancer

patients (Ellis et al., 2017; Patterson, Pearce, et al., 2011). Supporting previous work, results in this study highlight having a parent with cancer can have a high emotional impact on children. For one participant this was illustrated in her preference for talking and asking questions about her Mum's cancer and her struggle in opening up about how she feels. This could be out of fear of upsetting the parents by sharing how they feel or not knowing how to (Kennedy & Lloyd-Williams, 2009; Rodriguez et al., 2018). As the meta-analysis by Ellis et al., (2017) shows, providing young people with a supportive environment to open up about their feelings will enable them to do so. This does not always have to be found within the family but can also be outsourced. As discussed by Jack and Daniel, support from professional sources can be valuable when facing such a tough situation. Both participants disclosed having seen counsellors at the time of their interviews and the value that this added to their coping process. For some however, accessibility and awareness of such supports is not the only barrier to getting external support. For Rachel, who was described as not being one to talk much, external sources did not add much value to her coping ability. Although girls are shown to be more interested than boys in knowing more about their parent's cancer (Kennedy & Lloyd-Williams, 2009), this was not the case for Rachel.

By providing genuine and helpful support, children of cancer patients are better able to share their emotional experiences, which can in turn help them to process and alleviate these stressors.

Theme three: Time.

The concept of time was an important aspect for many children in the current study, as there was a need to know more about the process and timeframes pertaining to their parent's cancer and more time with them. Daniel (aged 12) and Kaitlyn (aged 9) articulated the value in more time spent with their Dad, as it was something that brought them joy during a tough experience. Likewise, adolescents who lived away from home for university shared

that time with the parent was highly valued, with changes being more noticeable than if they lived at home. The shock for Jack due to the physical changes his Mum experienced was great. He shared for him, it would have been better being home rather than living away, as the shock may have been less impactful. This knowledge reveals the depth of the impact that parental cancer can have on children and a greater need to spend more time with them.

Being at home and able to help out around the house has been shown to increase feelings of inclusion through the child actively contributing and maintaining a sense of normality (Maynard et al., 2013). Results from this research demonstrated a sense of urgency when it came to doing tasks around the house. There was also an increased willingness to do tasks such as make a cup of tea for parents and allow the sick parent more rest and sleep. Through increased awareness of the illness's severity and impact, children displayed an increased desire to help out and alleviate any household stressors from the parents (Phillips, 2015). Yet for others who live away from home, like Jack (aged 19), helping out could mean spending time researching different potential treatments for their parent. By doing jobs such as these for the sick parent, it can lead to both feelings of inclusion and extra time with them.

Uncertainty of the illness and prognosis, worries and anxieties can be fuelled, especially with a lack of information about their parent's cancer (Phillips & Lewis, 2015). More specifically from the current study, one participant stated that understanding what the timeframe would be and the process for what his Mum was going through helped him to be more realistic about the situation. Knowing an approximate timeline of what to expect can help children prepare for what may come and aid them in processing their parent's illness better. Likewise, children want to know what will happen to them and their parents, especially daughters whose mothers have cancer (Kennedy & Lloyd-Williams, 2008). However, Rachel did not appear to have a need for this information. Thus emphasising that every child is different and requires different information at different stages.

Theme four: Communication.

Communication is endorsed by children throughout the literature as a crucial component for adjustment and coping (Ellis et al., 2017). Open communication is shown to alleviate distress in children (Meriggi et al., 2017) and dispel any misconceptions which they may have about their parent's situation (Semple & McCaughan, 2013). Yet communication encompasses aspects of feelings and support, not just information-giving (Kennedy & Lloyd-Williams, 2008). Children in the current research mentioned five components of communication which were important to them, including communication with school, at the start, being open, having the conversation, and talking about the positive. Children who are still at school indicate a need to feel supported by teachers and peers, as school is typically seen as a place of reprieve from their situation at home (Chowns, 2013). In the current research, Daniel had mixed feelings about school, suggesting that it may be dependent on the situation at home (i.e. the state of the parent's illness) and the workload at school. Through open communication with and awareness from the school, the child can be provided with the help they need. As was the case with Daniel.

Across the literature, being told of the illness at the start, or as close to the diagnosis as possible is essential for many children and their ability to cope (Davey et al., 2011; Huang et al., 2014). This is because children want to feel included in what is happening at home. If children are not told, some are shown to pick up that something is wrong and may even go looking for answers themselves (Finch & Gibson, 2009). This in turn is shown to increase distress and anxiety due to inaccurate answers, inaccurate for their parent's situation, and/or worse-case scenarios. Unlike the research above, the responses from Jack and Daniel highlight the impact that not being informed straightaway can have on children. Including potential feelings of anger, sadness, and annoyance. Although both of them understood and let go, it can lead create tension within the family. There was an understanding that it may

have been for their own protection so as not to overwhelm them. Children not only are aware of the illness and not being told, but also why they might not have been told. Indicating the forgiveness level of children. Although there is variation in how families communicate and how much, many studies show that it is important yet can be difficult to achieve sometimes (Kennedy & Lloyd-Williams, 2008). In Rachel's situation, she struggles discussing how she feels and asking questions, especially with her family. As observed during the interview, discussing such a serious topic was difficult for her and still bothered her. Not only do parents struggle with communicating, but so do children. Communication needs to be a two-way street between all family members (Silver & Silver, 2013). By contrast, Jack felt as though he had a good relationship with his parents and felt comfortable telling them how he was feeling. A finding by Patterson et al., (2011) showed that higher family cohesion was associated with greater unmet needs relating to information as parents may not appreciate the amount of information needed, which may prevent the child from asking questions. Yet in the case of Jack and Daniel, this was not the case. Every family is different, and every child varies in when and how they want information, in addition to the amount and the type. Having the option to know more or to know less was essential to Daniel (aged 12), as at times it appeared to be overwhelming and other times it was not enough. Keeping communication lines open therefore allows the family to work in a way which is beneficial to all members.

Having the conversation was an important subtheme which appeared in three out of four of the interviews. This involved making room and time to discuss the illness and what it meant for them and their family regarding what was going to happen. With Jack living away from home, this was even more pertinent, as he was not aware of what was going on. Thus, discussing with him what was going on and what to expect was important. By having the conversation about what the parent is going through and what can be expected, the child is better prepared and has a greater understanding of cancer and all of its components (Maynard

et al., 2013). As found in Huang et al.'s, (2014) study, children want to be informed of the illness and be able to seek information if they want. For Jack, he shared that having the option to know what was going on would be nice, yet in order to achieve this. However, the parents need to have the conversation with the child and update them on the parent's cancer for them to be informed. Which in turn can aid in them seeking additional information if needed or wanted.

Without information on all aspects of cancer, the good and bad, it is easy to assume the worst. Children in the current study wanted to know both the good and bad, which supported previous findings that illustrate the value in discussing the good aspects (Kennedy & Lloyd-Williams, 2009). Two children interviewed in the current research shared that they wanted to be told about the good aspects of the cancer and what their parent was going through. In comparison to work by Kennedy and Lloyd-Williams (2009), the current research expands upon this through providing examples of what children may want to know. Sharing improvements and discussing the impact of the treatments has been shown to provide a sense of hope. And as Jack (aged 19) shared, being realistic about the situation was important to him, which indicated that both sides of the information need to be disclosed for children to have a better understanding of what is going on. To achieve this, Jack revealed having outsourced information on potential treatments for his Mum through reading theses for her. These findings highlight the importance of discussing information about all aspects of the parent's cancer; its severity, the negative aspects, treatments, benefits, and the positive components. This can in turn aid them in thinking more positively and realistically, which can benefit their ability to cope (Maynard et al., 2013; Phillips & Lewis, 2015).

Theme five: Awareness of Others.

Children appear to display a great level of awareness and empathy towards others both in the current study and previous findings (Kennedy & Lloyd-Williams, 2009; Silver &

Silver, 2013). Children vary in how they react to being told and vary in what they need (Huang et al., 2014; Walczak et al., 2018), yet one consistency is the empathy that they exhibit. However, the way this was portrayed was through 'other-focused' answers. When asked what would be beneficial in terms of support and resources, Jack and Daniel showed a great appreciation for what other children may require who are in a similar situation. Many young people typically report wanting support from peers and teachers, access to support services, and more information in an age-appropriate way (Patterson, Pearce, et al., 2011). Yet Daniel's (aged 12) response was initially of what other children might need, saying that they would probably want more of a choice. He went on to say that there are some children like him who do not need professional help because they are aware of what is going on, but for others who are sad due to being separated from their parents, they might. This supports previous work by Phillips (2015) which showed that there was an increased appreciation for the needs of others; a deeper understanding of what others go through out of their own experience. Likewise, in the case of Jack (aged 19), when asked if it would be better to be at home or away in a different city, his response was other focused rather than self-focused. This suggested that because of his situation, he was aware that others may be different to him when it came to being removed from the cancer situation or not. This highlights that children are aware of differing needs and can provide genuine empathy out of experiencing a similar situation.

Theme six: Family separation.

A cancer diagnosis within the family creates many disruptions to the functioning of the family due to hospital visits and lengthy treatment stays (Faulkner & Davey, 2002; Phillips & Lewis, 2015; Rodriguez et al., 2018). It is suggested that families who live rurally face different challenges to those who live in larger cities. As a result, they may face increased work and financial demands, and longer periods of separation as a result of longer

travel times and hospital stays (Garrard et al., 2017). In line with these results, the current research highlighted the toll that family separation has on children and their mental and emotional well-being. Yet this was from a New Zealand context, where family separation during cancer treatment may be more prevalent due to longer travel time due to distance away from treatment centres. Siblings Daniel and Kaitlyn, who live just under two hours away from a main city, shared that they were separated from their Dad for seven weeks. This impacted their emotions, as they were upset and concerned being away from their Dad. Little research has been done on families who live rurally or live a distance away from large cities which house treatment centres and hospitals. These findings help fill this gap in the literature by providing an insight into how long families may be separated for and the impact that it has on children. When asked, Daniel (aged 12) indicated that those who cannot see their parents might want more of a choice of support just like he did when he could not see his Dad. As a result, there may be a greater level of support required for this group.

In a similar manner, children who live away from home because of university may face poorer adjustment. As Rodriguez et al., (2018) found, one participant showed poor adjustment to their Mum having cancer and ended up moving back home to cope better and be present for her Mum. Whereas for the other two, the more family-based resources they had, the better they were able to balance the maternal cancer experience and university life and workload (Rodriguez et al., 2018). In the current study, Jack (aged 19) shared that because he lived in a different city to his parents, it was hard for him as he did not see what was going on all the time, which in turn made the adjustment to his Mum's cancer more difficult and overwhelming. As Jack shared, one of the most challenging parts was being away from home at university for extended periods of time and then going home for the breaks, seeing the physical changes that his Mum was going through, and struggling to get used to that. The added pressure of being separated from the family can challenge a child's

ability to cope, as changes can be more overwhelming and upsetting when they are less gradual.

Conclusion

Overall, the themes and subthemes which emerged from this research highlight the variations in support and information needs amongst children who have a parent living with cancer. Although there are similarities with previous research, the findings add to an emerging body of knowledge from a New Zealand perspective, providing greater insight following the experiences of young people who have a parent living with cancer. This perspective and valuable to healthcare professionals and cancer organisations, in New Zealand.

Due to the rurality of three of the participants within this research, experiences are different to those who live within larger cities, as less travel and separation is experienced. Therefore the needs of each child should be addressed on an individual basis.

Limitations

The main limitation in this research is the sample size. This was largely as a result of a timing issue with organisational challenges for the main children's cancer support agency. Due to the small sample size, the results cannot be generalised to all children who have a parent diagnosed with cancer. However, the results can assist healthcare professionals and organisations working with these families to better understand the needs of these children. It is important to keep in mind that the children interviewed have not had adequate contact with support organisations such as Canteen. Therefore, the responses from children who have had support agency contact may have offered different responses. This study did not include a retrospective look whereby the parent is in remission or the family is bereaved. It only considered those currently living through the experience of diagnosis and treatment. A

retrospective study may offer helpful information, but with caution as responses may vary due to memory and/or emotions.

Limitations are also apparent when interviewing young people as there is often a heavy reliance upon the willingness of families to allow their children to participate (Noon, 2018). This is even more prominent with a sensitive topic and the targeted age group of children (7-19 years). What they choose to discuss is sensitive in nature and may bring forth a range of emotions such as of distress, sadness, anger, and confusion. Although the respondents were mixed in age and gender (two girls, two boys, between 9 and 19 years), the results are not a true representation of children in New Zealand who have a parent diagnosed with cancer. These participants lived outside of where the main cancer treatment centres are located, therefore experiences may be different to those who live within a large city. Additionally, obtaining interest and participation through cancer-focused organisations may offer the potential for self-selection bias. This is because these may be people who are more likely to participate in interviews than others who are not linked with a support agency. There may be many families within New Zealand who do not have access to or are aware of such organisations. Thus, this may restrict the range of individuals who participate in studies such as this one.

The chosen method of one-on-one interviews also comes with limitations. Although interviews within the participant's home can be supportive and provide a more relaxed and familiar environment, there is the potential for the family, and even the sick parent, to be present. This may cause respondents to withhold some information about how they are coping and what they are wanting in relation to information and supports. As seen during one interview with the child, the Mum also took part. Even though this gave a better insight into how the child coped and what she, as the parent thought would be beneficial, the participant was quiet during the interview. This could have been due to not being a talkative person or

not wanting to share too much for fear of upsetting her Mum. Therefore, having separate interviews with the child and then the parent may offer more robust findings.

Recommendations for Future Research

This research provides further understanding and insight into the experiences of young people who have a parent diagnosed with cancer from a New Zealand perspective. In line with other research (Davey et al., 2011; Kennedy & Lloyd-Williams, 2009; Maynard et al., 2013; Phillips & Lewis, 2015; Walczak et al., 2018; Wilkins & Woodgate, 2005; Wong et al., 2010), children of cancer patients present an array of different needs. Of particular interest to the current study were the specific needs regarding communication, information, and support. However, because the current study was not able to investigate the needs of siblings alongside children due to issues faced in the recruitment phase, future research would benefit by investigating the needs of siblings. This is so that researchers and health practitioners have a better understanding of what young people need as a collective when they have a family member diagnosed with cancer. This in turn would aid organisations and health professionals to design and implement more effective resources and supports tailored to their needs.

Although data was not collected on ethnicity, all participants were of New Zealand/European descent. This highlights the need for a more ethnically diverse range of participants so that results can be more generalisable to the wider New Zealand population. By doing so, different cultures can be represented and therefore add more insight to this topic. Similarly, future research would benefit from having a larger cohort of participants. Although phenomenology, due to its in-depth approach of data analysis, does not require a large number of participants (Creswell, 2007), having a larger sample size would allow more generalisability to children in Aotearoa, as well as provide a better insight to and understanding of these young people. Due to time restrictions on the current study and issues

faced during recruitment, less narratives were heard, which did not provide a wide picture of the lived experiences of children.

Although one-on-one interviews are beneficial by having the freedom to ask more in-depth questions and obtaining a richer insight into the lived experience of children, there are issues faced due to the sensitive nature of the topic. As one member of the organisation 'Sweet Louise' said, due to the severity of some situations, families may be less likely to allow their child to participate out of fear of upsetting them. Therefore, future research would benefit from asking parents as well, in order to obtain a greater understanding of the child's experience. However, it is important that, if possible, this is done separately as there is a risk of the child or the parent adjusting their behaviour and/or responses in a way that does not upset the other. During one interview in the current study, one participant had her Mum present, which may have hindered the child's responses out of worry about upsetting her Mum. Thus, it is important to conduct these interviews separately, as there is value in responses from both the parent and the child.

Lastly, based on responses from the current research, future studies would benefit from investigating the availability and awareness of information and support resources through working more closely alongside cancer-based organisations. Due to lack of time and issues faced within this research during recruitment, such an investigation was not able to be achieved. By obtaining information on how organisations contact and communicate with cancer patients who have children, organisations and healthcare professionals will have a better understanding of how this need can be met.

Implications for Practice

It is vital to ask children about their experiences and what they need in terms of information and support, so that they can be better assisted. Although there has been an increase in research in this area (Kennedy & Lloyd-Williams, 2009; Patterson et al., 2017),

there are only two studies within a New Zealand context (Lamb, 2015; Porteous et al., 2018). However, both of these studies focused on the lived experiences of siblings. Due to the different types of relationships between the parent-child and sibling-sibling dyads, the current study provides an insight into the different experiences of these children. This can further help health professionals in supporting these young people and meeting their needs with the types of information that they require.

Though the sample size is small, these findings highlight the importance of asking children about their experiences and what support and information they need, as well as ensuring organisations are aware of children's needs and making resources accessible. Although children in the current study did not feel that they needed external supports (e.g. a support group) as they either had access to a professional at school or they felt better by knowing what was going on, three mentioned the need for better information. Specifically, information on the positive aspects of their parent's cancer. Prior research shows that by maintaining a positive mind-set, it can help in the adjustment of children (Porteous et al., 2018), which can be sustained through knowing not just the tough aspects, but the good as well. One way which was suggested in the current study is through the creation of resources specific to different types of treatments.

Additionally, there was a lack of awareness and availability of resources that the children could access. Many of the participants indicated a need for more awareness of what is available if they would like it. Similar to other research (Finch & Gibson, 2009; Kennedy & Lloyd-Williams, 2009), there seems to be a lack of communication between organisations and families, with the parent of one participant saying *"nobody's ever talked about websites".* Increasing the awareness that organisations have of the needs of children, especially of the families who come into contact with them, may help in communication between the two groups. In turn they could provide necessary support in how, firstly, parents

can communicate with their child, supplying them with information early on. Secondly, offering children supports that they can utilise, and readable resources tailored to their age and interest in what they want to know. The hope from research is that there would be an increase in awareness of children who have a parent diagnosed with cancer and a growth in accessible and available resources.

Concluding Thoughts

This research aimed at investigating the support and information needs of children of cancer patients through obtaining their lived experience of having a parent living with cancer. Through the utilisation of semi-structured interviews, four children aged nine, twelve, eighteen, and nineteen shared their experiences and what they wanted more of in regard to supports and information.

Although challenges were faced during recruitment, responses from the four participants provide greater depth and insight into the experiences of children within a New Zealand context whose parents live with cancer. Utilising this information, organisations and healthcare professionals in New Zealand can now tailor how they interact with these children and their families, in addition to the resources that they supply.

This research highlights the value of talking with children to get their insight and the variations in what each child requires to cope. Especially as each situation and experience is different to another.

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Appendices

Appendix A – Ethics

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

HUMAN ETHICS COMMITTEE

Secretary, Rebecca Robinson
Telephone: +64 03 369 4588, Extn 94588
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2019/50

11 July 2019

Lauren Clark
Health Sciences
UNIVERSITY OF CANTERBURY

Dear Lauren

The Human Ethics Committee advises that your research proposal "Information Needs of Young People of Relatives Living With Cancer" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 9 July 2019.

Best wishes for your project.

Yours sincerely

Dr Dean Sutherland
Chair
University of Canterbury Human Ethics Committee

College of Education, Health, and Human Development.
Telephone: 021 255 3982
Email: lauren.clark@pg.canterbury.ac.nz
29th April, 2019
HEC Ref: [Enter when approval given for your study]

Information needs of children of parents with cancer. Information Sheet for Parents/Guardians/Caregivers of Children Participants.

My name is Lauren Clark and I am a Master's student at Canterbury University. I am carrying out my Master's thesis, investigating the information and support needs of young people who have a sibling or parent with cancer. My aim is to use this confidential information to advocate for the production and use of appropriate resources and supports.

You have been approached to take part in this study because as I am interested in understanding the experiences of children who have a sibling or parent who has been diagnosed with cancer and/or going through treatment for it, in order to design better supports. I have located your contact details through the Cancer Society, the Child Cancer Organization, or the CHOC ward.

If you choose for your child to take part in this study, their involvement in this project will be an hour of their time in either (a) a one-on-one interview with myself (primary researcher), (b) a small and supportive focus group, or (c) writing down answers to the questions. They will be asked a couple of open-ended questions on how they perceive their experience when it comes to communication about and support for them during yours or your child's cancer and treatment.

Due to the sensitive nature of the topic and questions asked, there is the potential for your child to experience a variety of feelings for example, sadness, stress, frustration. Therefore, we will provide all support necessary and all questions will be asked with the utmost sensitivity and respect.

Participation is voluntary and confidential, and you and/or your child have the right to withdraw at any stage. You may ask for your child's data to be destroyed at any point. If you withdraw, I will remove information relating to your child. However, once analysis of data starts in July, it will become increasingly difficult to remove the influence of your child's data on the results.

The results of the project may be published, but you may be assured of the complete confidentiality of data gathered in this investigation: your child's identity will not be made public and all names will be changed to ensure confidentiality. To ensure anonymity and confidentiality, once recordings have been transcribed and written down, all recordings will be kept for 5 years as per the UC policy. Names will not be used at any time except for when in the focus groups for rapport and trust to be built and will be deleted when the recordings are transcribed. Pseudonyms can be used if you and/or your child would like. Those who will have access to the recordings will be the two researchers – myself (Lauren Clark) and my Supervisor Kate Reid – as well as the transcriber. The data will be stored on a recorder and kept at the campus in a secure office. A thesis is a public document and will be available through the UC Library.

Please indicate to the researcher on the consent form if you would like to receive a copy of the

summary of results of the project.

The project is being carried out as a requirement for a Master's degree in Child and Family Psychology by Lauren Clark under the supervision of Kate Reid who can be contacted at kate.reid@canterbury.ac.nz. She will be pleased to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

If you agree to participate in the study, you are asked to complete the consent form and return to Lauren Clark after signing.

Appendix C – Parental Permission Form

College of Education, Health, and Human Development.
Telephone: 021 255 3982
Email: lauren.clark@pg.canterbury.ac.nz
29th April, 2019
HEC Ref: 2019/50

Parental Permission for Children Participation in Research

Title: Information Needs of Young People of Relatives Living with Cancer.

Introduction

The purpose of this form is to provide you (as the parent of a prospective research study participant) information that may affect your decision as to whether or not to let your child participate in this research study. The person performing the research will describe the study to you and answer all your questions. Read the information below and ask any questions you might have before deciding whether or not to give your permission for your child to take part. If you decide to let your child be involved in this study, this form will be used to record your permission.

Purpose of the Study

If you agree, your child will be asked to participate in a research study about their experiences of having a parent or sibling diagnosed with and treated for cancer. The purpose of this study is to investigate their information and support needs when it comes to being told about cancer in their relative, so that they can better understand the illness and be supported.

What is my child going to be asked to do?

If you allow your child to participate in this study, they will be asked to either:

a. Discuss in a small focus group of 4-6 other children in a similar situation their experiences with having a relative live with cancer.
   OR
b. Write down their experiences with having a relative live with cancer.
   OR
c. Have a one-on-one interview with the researcher, being asked about their experiences of having a sibling or parent living with cancer.

This study will take approximately 1-2 hours and there will be approximately 4-6 other children in the focus group. Baking will supplied so that they have something to munch on.

Note: Your child will be audio recorded.

What are the risks involved in this study?

NOTE: This study may involve risks that are currently unforeseeable. Possible risks include negative feelings such as sadness due to the sensitivity of the topic. The likelihood of this depends on the child. The researcher has made sure that there are support staff outside if the need arises, and the children will be asked if they are okay to keep going every so often throughout. Due to my background in developmental psychology and working with young people on a regular basis, I am aware and sympathetic towards their emotional and psychological needs.

What are the possible benefits of this study?

Note: Your child will receive no direct benefit from participating in this study; however, information gathered in this study will allow for future research to design and implement better resources to support children going through similar situations.

Does my child have to participate?

No, your child's participation in this study is voluntary. Your child may decline to participate or to withdraw from participation at any time. Withdrawal or refusing to participate will not affect their relationship with any of the organizations or the University of Canterbury. You can agree to allow your child to be in the study now and change your mind later without any penalty.

What if my child does not want to participate?

In addition to your permission, your child must agree to participate in the study. If you child does not want to participate, they will not be included in the study and there will be no penalty. If your child initially agrees to be in the study, they can change their mind later without any penalty.

Will there be any compensation?

NOTE: Neither you nor your child will receive any type of payment participating in this study. However, there will be baking and juice or water for their participation whilst in the focus group. If your child has any dietary requirements (e.g. gluten free, dairy free), please notify me prior.

How will your child's privacy and confidentiality be protected if s/he participates in this research study?

Your child's privacy and the confidentiality of his/her data will be protected by secure storage on University computers and data will be anonymous. This will be done through no names being placed on any of the recordings, and the recordings will be deleted 5 years after the submission of the study.

If you would like your child to use a pseudonym for the purposes of this study, please write it in the space provided below.

NOTE: If you choose to participate in this study, your child will be audio recorded. Any audio recordings will be stored securely and only the research team will have access to the recordings. Recordings will be kept for 5 years and then erased.

Whom to contact with questions about the study?

Prior, during or after your participation you can contact the researcher, Lauren Clark on 021 255 3982 or send an email to lauren.clark@pg.canterbury.ac.nz for any questions or if you feel that you have been harmed. This study has been reviewed and approved by The University Institutional Review Board and the study number is **[STUDY NUMBER].**

Whom to contact with questions concerning your rights as a research participant?
If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

You can also contact the ethics committee that approved this study on:

University of Canterbury Human Ethics Committee
Phone: 03 364 2987
Email: human-ethics@canterbury.ac.nz

Please indicate whether you would like to receive a copy of the summary of results of the project. ❑ Yes ❑ No
Email: _____

Signature

You are making a decision about allowing your child to participate in this study. Your signature below indicates that you have read the information provided above and have decided to allow them to participate in the study. If you later decide that you wish to withdraw your permission for your child to participate in the study, you may discontinue his or her participation at any time. You will be given a copy of this document.

_____ _____
Printed Name of Child Pseudonym for Child

_____ _____
Signature of Parent(s) or Legal Guardian Date

_____ _____
Signature of Investigator Date

Appendix D – Information Sheet for 14 to 18-year-olds

College of Education, Health, and Human Development.
Telephone: 021 255 3982
Email: lauren.clark@pg.canterbury.ac.nz
29th April, 2019
HEC Ref: [Enter when approval given for your study]

Information needs of children of parents with cancer.
Information Sheet for 14 to 18-year-olds.

My name is Lauren Clark and I am a Master's student at Canterbury University. I am carrying out my Master's thesis under the Child and Family Clinical Psychology programme, investigating the information and support needs of young people who have a sibling or parent with cancer. My aim is to use this confidential information to advocate for the production and use of appropriate resources and supports.

You have been approached to take part in this study because as I am interested in understanding the experiences of children who have a sibling or parent who has been diagnosed with cancer and/or going through treatment for it, in order to design better supports The Cancer Society, the Child Cancer Organization, or the CHOC ward have approached you as a potential participant due to you meeting the criteria related to this study.

If you choose to take part in this study, your involvement in this project will be in either (a) a one-on-one interview with myself (primary researcher), (b) a small and supportive focus group, or (c) writing down answers to the questions. You will be asked a couple of open-ended questions on your experience when it comes to communication about and support for them during yours or your child's cancer and treatment.

Due to the sensitive nature of the topic and questions asked, there is the potential for you/your child to experience a variety of feelings for example, sadness, stress, frustration. Therefore, we will provide all support necessary and all questions will be asked with the utmost sensitivity and respect.

Participation is voluntary and confidential, and you have the right to withdraw at any stage. You may ask for your data to be destroyed at any point. If you withdraw, I will remove information relating to you. However, once analysis of data starts in July, it will become increasingly difficult to remove the influence of your data on the results.

The results of the project may be published, but you may be assured of the complete confidentiality of data gathered in this investigation: your identity will not be made public and all names will be changed to ensure confidentiality. To ensure anonymity and confidentiality, once recordings have been transcribed and written down, all recordings will be kept for 5 years as per the UC policy. Names will not be used at any time except for when in the focus groups for rapport and trust to be built and will be deleted when the recordings are transcribed. Those who will have access to the recordings will be the two researchers – myself (Lauren Clark) and my Supervisor Kate Reid. The data will be stored on a recorder and kept at the campus in a secure office. A thesis is a public document and will be available through the UC Library.

Please indicate to the researcher on the consent form if you would like to receive a copy of the

summary of results of the project.

The project is being carried out as a requirement for a Master's degree in Child and Family Psychology by Lauren Clark under the supervision of Kate Reid who can be contacted at kate.reid@canterbury.ac.nz. She will be pleased to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

If you agree to participate in the study, you are asked to complete the consent form and return to Lauren Clark after signing.

Appendix E – Assent Form for 13 to 18-year-olds

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Youth (13-18 years) Assent Form for Participation in Research

Title: Information Needs of Young People of Relatives Living with Cancer.

Introduction

This form is to provide you with information on the study, what you will be involved in doing if you and your parent agree to participating, and giving you the option to either take part or not.
The researcher will describe the study to you and answer all your questions.
Please read the information below and ask any questions that you may have before you decide whether you would like to participate or not. Once both you and your parent(s) agree or disagree to participate, this form will be used to record your permission.

Purpose of the Study

If you agree, you will be asked about your experiences of having a parent or sibling diagnosed and treated for cancer. The purpose of this study is to investigate your needs when it comes to information and support during this experience. This is so that you can have access to support and information that meet these needs. This information will also be used to help other young people in a similar situation.

What will you be asked to do?

If you and your parent(s) do agree to you participating, you will either:

a. Discuss in a small focus group of 4-6 other youth in a similar situation their experiences with having a relative living with cancer.
   OR
b. Write down your experiences with having a relative living with cancer.
   OR
c. Have a one-on-one interview with the researcher, being asked about your experiences of having a sibling or parent living with cancer.

This study will take approximately 1-2 hours and there will be approximately 4-6 other youth in the focus group. Baking will be supplied so that you have something to munch on.

Note: You will be audio recorded, but all recordings are private and only used by the researcher.

What are the risks involved in this study?

NOTE: This study may involve risks that are currently unforeseeable. Possible risks may include feeling sad or down because of the topic. This is all completely normal and there will be support staff for you to have access to if you need and want. Throughout the focus group, interview, or the writing down of your answers, you will be asked by the researcher if you are okay to keep going or if you would like a break.

What are the possible benefits of this study?

Note: There will be no direct benefit from participating, but the information which you offer the researcher will help future research to create and improve the resources and supports for young people like you going through a similar situation.

Do you have to participate?

No; participation is voluntary. You may decline to participate or to withdraw from participation at any time. You and your parents can agree for you to be in the study now and change your mind later without any penalty.

What if your parent does not want you to participate?

In addition to your permission, your parent(s)/caregiver(s) must also be aware of the study and agree to allow you to participate. If they do not agree, you will not be included and there will be no problem with that.

Will there be any compensation?

NOTE: There will be no type of payment for participating in this study. However, there will be baking and juice or water for your participation whilst in the focus group.

How will your privacy and confidentiality be protected if you participate in this research study?

Your privacy and the confidentiality of your data will be protected by secure storage on University computers and data will be confidential.

All names will be removed when transcribing the recordings .and the recordings will be deleted 5 years after the submission of the study.

If you would like, you can choose to use another name for the purposes of this study. If you wish to do so, beside your printed name below, there is a space for you to write this.

Whom to contact with questions about the study?

Prior, during, or after your participation you can contact the researcher, Lauren Clark on 021 255 3982 or send an email to lauren.clark@pg.canterbury.ac.nz for any questions or my supervisor Kate Reid kate.reid@canterbury.ac.nz. This study has been reviewed and approved by The University of Canterbury Human Ethics committee.

Whom to contact with questions concerning your rights as a research participant?

Should you require additional support after taking part in this study, you may wish to contact a Health and Disability Services Consumer Advocate. They can be contacted on Freephone 0800 555 050.

If you wish to make a formal complaint about the care of your friend or family member, you can contact the Health and Disability Commission at www.hdc.org.nz/complaint.

Signature

You are making a decision about agreeing to participate in this study. Your signature below indicates that you have read the information provided above and have decided to participate in the study. If you later decide that you wish to withdraw your permission to participate in the study you may discontinue your participation at any time. You will be given a copy of this document.

Appendix F – Children's Information Sheet

Children's Information Sheet

Title: Information needs of young people of relatives living with cancer.

What is this study about?

This study asks questions about your experiences of having a parent or a brother or sister with cancer. You will also be asked if you feel supported and if you have been told things about the illness and the treatment. What I find will then help with making booklets and supports for you and others who are going through a similar experience.

What will I be doing?

This study means, if you want to, you will be sitting in a circle with other children and answering questions about what it is like to have a parent or a brother or sister who has cancer. Or, if you would like to, you will be able to write answers to questions or to sit with just the researcher and a parent to answer questions.

You and your parents will be asked if you want to and can participate. Once you have been told what is involved, your parents and you will fill out forms to say, "Yes I do want to participate" or "No I do not want to participate".

You will be asked a few questions and you can talk for as long or as short as you would like.

You do not have to answer all the questions, and if you start to feel sad, that is okay. If you do not want to continue answering and want to leave, that is okay too.

What happens after?

The answers that you give will only be heard by myself, the other researcher, and the other children in the room. Nobody else will hear them or know that you participated.

The information that I receive will then go into a big document that will tell me how you feel and what more needs to be done so that we can give you and others like you, the best support.

How can I find out more?

Your Mum, Dad, or Caregiver may be able to answer any questions. You can also ask me more questions if you are confused or want to know more.

Appendix G – Children's Assent Form

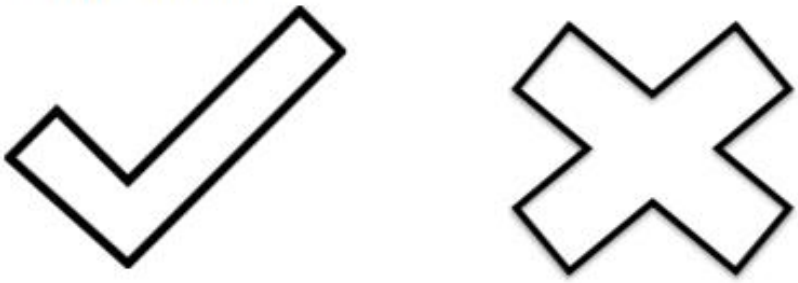
Children's Assent Form

The project that Lauren wants to do about Cancer support has been explained to me. I know I do not have to do it if I don't want to. If I have any questions, I can ask my parent or Lauren.

- I am keen to be part of the project and to talk about my experiences with Lauren and some other children, so I have coloured in the tick.

OR

- I don't want to be part of the project or to talk about my experiences with Lauren, so I have coloured in the cross.



My name: _____

Please give this back to your parent now.